Results of the 2006/2007 Hospice Patient Survey

General Report

CHSS
University of Kent

help the hospices

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Funding and acknowledgements

This research was funded by Help the Hospices, Hospice House, 34-44 Britannia Street, London and by the 53 Hospices who agreed to take part in the survey, to whom we are grateful. We would also like to thank all the patients who took part in the study.

Help the Hospices is the National Charity for the hospice movement.

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Executive summary

- The National Minimum Standards for Independent Healthcare, published in 2002 by the Care Standards Commission (now the Healthcare Commission), states that hospices are required to conduct an annual patient survey. In response to this, a Patient Survey Group (with representation from independent hospices, Marie Curie Cancer Care and with input from the Care Standards Commission) was set up by Help the Hospices. Its goal was to develop a questionnaire suitable for use in all adult hospices. The 2006/07 survey is now the second survey conducted in response to this requirement. The first Patient Survey was conducted in 2004/05.

- This report details the findings for the 53 Hospices participated in the second patient survey circulated in 2006/2007. The self-complete survey incorporated questions relating to: information giving; staff attitudes; patient involvement in care planning; confidence in staff; privacy and respect; catering and hygiene; awareness of the process for complaints; and support when patients were discharged or had died. 1352 questionnaires were returned from daycare patients and 1052 from inpatients.

- This report provides individual hospices with their results for daycare and inpatients separately. It also provides benchmark results (includes only hospices with at least 40 responses) and results for all the participating hospices, both in tabular form and a summary of patient's written comments. Slightly higher rates of excellence are noted in the daycare benchmark and lower rates of excellence are noted for the inpatient benchmark, compared to the overall results.

- Daycare patients and inpatients responses were quite similar and extremely positive, although daycare patients showed slightly higher levels of satisfaction in most comparable questions.

- 67% of daycare and 65% of inpatients were aware of the information leaflets and nearly all found them helpful and easy to understand. Three quarters of daycare and inpatients felt they always had sufficient opportunity to ask question they wanted to about their care.

- Patients expressed very high levels of confidence in the staff, in their care and the number of staff available. The vast majority thought the staff always treated them with respect. 85% of daycare patients said staff always introduced themselves and 83% said staff always tried to meet their needs and wishes, the percentage for these questions was slightly less for inpatients.

- Patients expressed the highest level of satisfaction with cleanliness, particularly in daycare (90%) compared to inpatients (72%). Similar results were found for the general environment: 79% for inpatients and 87% for daycare. To a lesser degree they were also satisfied with the catering (67%-68%). The slightly lower satisfaction being expressed by inpatients.

- Daycare patients were asked about transport and the vast majority of users rated this at the highest level. Daycare patients were quite satisfied with the range of available activities (64%).

- 90% of inpatients knew how to call for assistance and 70% of these were happy with the response time. 67% felt that they were given enough time to make decisions about their care.

- The lowest level of satisfaction was shown when a group member died or was discharged (daycare only). Less than half of the respondents, 50% of daycare and 48% of inpatients, felt extremely supported when someone had died. In daycare 41% said they felt extremely supported when someone was discharged.

- When asked for their comments on areas where the service could be improved, patients often responded with praise for the service they received; although some comments were made that hospices can act upon, the great majority of the comments were complimentary. On the whole the comments reiterated the same findings, but they do include a number of specific suggestions. Examples of these suggestions can be found in sections 4.4 and 5.4 of this report.

- When comparing these results it should be remembered that a different number of hospices achieved the benchmark in each survey and that only 2/9 benchmark hospices for inpatients and 5/10 benchmark hospices for daycare also achieved the benchmark in the previous survey.

1. Introduction

The National Minimum Standards for Independent Healthcare, published in 2002 by the Care Standards Commission (now the Healthcare Commission), states that hospices are required to conduct annual patient surveys:

> *'A patient survey is carried out annually, as a minimum to seek the views of patients on the quality of the treatment and care provided'* – National Minimum Standards for Independent Healthcare, Standard C6, National Care Standards Commission (NCSC).

In response to this, a Patient Survey Group (with representation from independent hospices, Marie Curie Cancer Care and with input from the Care Standards Commission) was set up by Help the Hospices with a goal to develop a questionnaire suitable for use in all adult hospices.

The resulting questionnaire developed by the group incorporated questions relating to information giving, staff attitudes, involvement in care planning, confidence in staff, privacy and courtesy, catering and hygiene and awareness of the process for making a complaint.

A pilot was first circulated to 17 hospices in 2003, followed by the first circulation in 2004/2005 and the most recent circulation in 2006/2007. Views of patients were sought to ensure clarity and ease of completion prior to finalising the pilot version and the subsequent circulations and the plain English "Crystal Mark" was also achieved for the latter questionnaire.

The anonymous questionnaire was circulated with pre paid envelopes to inpatients and daycare clients at discharge or after two months of attending daycare.

This report details the findings for the 53 Hospices that participated in the second patient survey between 1st July 2006 to 28th February 2007.

The questionnaires were returned to and analysed by the Centre for Health Services Studies at the University of Kent. The data from hospices, who achieved 40 or more returned questionnaires, has also been analysed in a benchmarking format. This separate benchmarking allows for individual hospices to compare their results against hospices that achieved a higher response, which is more statistically valid.

The benefits envisaged included prevention of duplication of effort and the opportunity to participate in a national benchmarking scheme. Hospices who did not take part have used their own methods of measuring patient satisfaction.

We hope you find this report useful.

Jan Codling, Chair – Patient Survey Group and Head of Clinical Governance St Ann's Hospices, Manchester.
Nick Pahl, Development Director, Help the Hospices.

2. Background

The idea of caring for people at the end of life has been developed over thousands of years but since the opening of the first modern hospice, St Christopher's in south London, in 1967, hospice care has grown into a worldwide movement that has radically changed approaches to death and dying with its desire to transform the experience of dying. It has been regarded by some as one of the greatest social innovations of the last hundred years.[1]

Hospice care and the services they provide are[2]:

- for those whose illness may no longer be curable, mostly cancer but increasingly other life-threatening illnesses
- enabling patients to achieve the best possible quality of life
- family support and bereavement services
- considering the whole person and offering physical, emotional and spiritual care
- trying to meet the needs of people from all cultures and communities.

Hospice inpatient services and daycare services, which are the focus of this survey, are just two types of service provision available to the public, others include hospital and home care. Admission as an inpatient in a hospice care unit may be required for control of symptoms, respite care and terminal care for patients who are in the very final stages of their illness. Hospice and palliative care service provide help mainly for people with cancer, but increasingly they are supporting patients with other life-threatening illnesses, such as Motor Neurone Disease, Multiple Sclerosis, HIV/AIDS and heart conditions. Provision of daycare services enables many patients to continue living at home while having access to hospice facilities. Daycare services may include medical and nursing care, spiritual support, physiotherapy, occupational therapy, complementary therapies, hairdressing, chiropody and beauty treatments as well as varied creative and social activities.[3]

[1] 'Hospice information' www.hospiceinformation.info/whatishospice.asp 09/06/2005
[2] 'Hospice and Palliative Care Directory: United Kingdom and Ireland 2007,' published by 'Hospice Information'
[3] 'Hospice and Palliative Care Directory: United Kingdom and Ireland 2007,' published by 'Hospice Information'

3. Methods

As in the previous survey the method of data collection on patient satisfaction with inpatient and daycare services in hospices was by self-completion questionnaire. One questionnaire was designed for the evaluation of daycare services and another for evaluation of inpatient services (Appendix A and B). A self-completion questionnaire was used as this enabled the collection of a large number of responses at relatively low cost.

Hospices across the UK were invited by letter to take part in the 2006/07 Patient Survey. The number of hospices choosing to participate in the survey was 53 hospices, the same number as the previous survey. In total 49 hospices participated in daycare and 48 participated in the inpatient survey. Some of these hospices participated in both and some took part in just one service. This time 44 hospices distributed questionnaires to both daycare services and inpatient services, five distributed questionnaires to patients using daycare services only and four hospices distributed inpatient services questionnaires only. Therefore the number of hospices participating in both services and in daycare only were slightly higher than the 2004/05 survey. Hospices invited that did not take part in the survey have their own method of measuring patient satisfaction in their hospice.

The survey was distributed only to adult inpatient and daycare units, but there were some other exclusion criteria. Patients with altered consciousness and altered cognitive ability were excluded depending on clinical judgement. Participating hospices distributed questionnaires to their own patients by printing off electronic copies and distributing them to inpatients at discharge and to daycare patients at discharge or after two months of attending daycare. The benefit of individual hospices printing off electronic copies was that hospices could tailor the instructions and style to fit their hospice and it enabled them to re-format the survey to help patients with visual impairments. It also allowed hospices to personalise the questionnaire by having it on different coloured paper and with their logo. In order to ensure validity and prevent any bias in the answers given, through inhibited responses, patients were asked to fill in the questionnaires at home rather than 'on the spot'. Carers of patients were allowed to complete the survey on behalf of patients if required, however the views recorded had to be the views of the patient and not those of the carer.

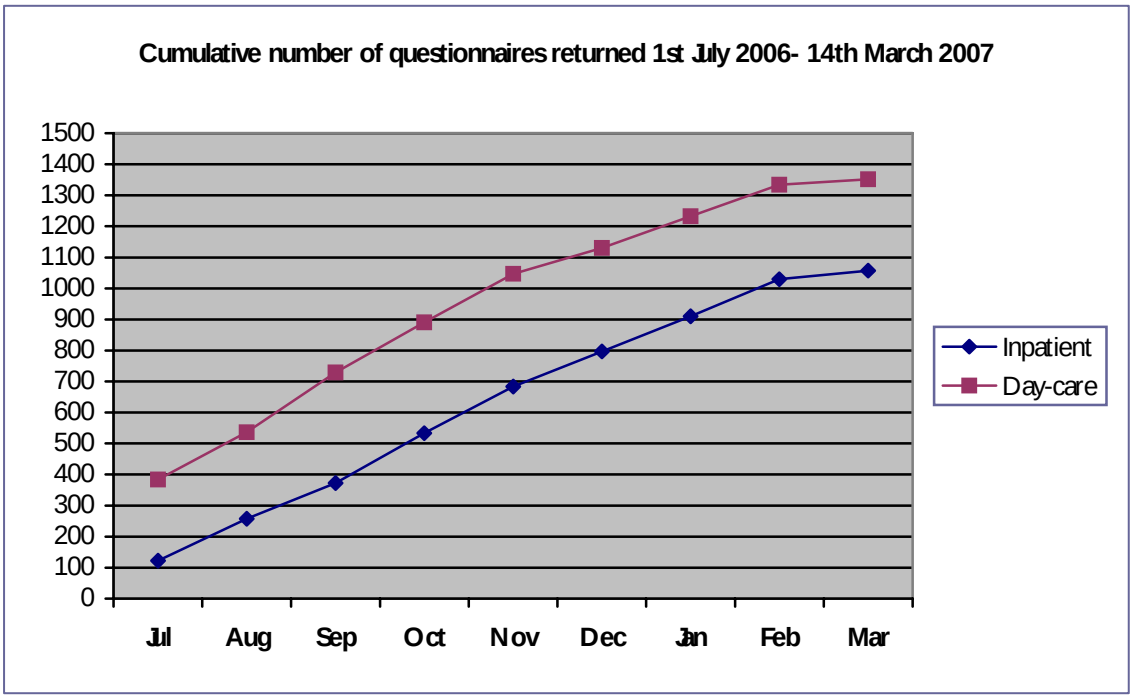
Patients were asked to return their completed questionnaires, which were anonymous, in pre-paid envelope provided to a third party organisation and not to the hospice themselves. The third party organisation was the Centre for Health Services Studies, based at the University of Kent, who also carried out the analysis and reporting the survey in their Health and Social Survey Unit. By using the approach of an independent third-party rather than the hospice themselves to return the questionnaire, it was hoped that response rates would be higher as patients may be less anxious about participating if they knew the questions would not be seen and analysed within the hospice where they may return for care.

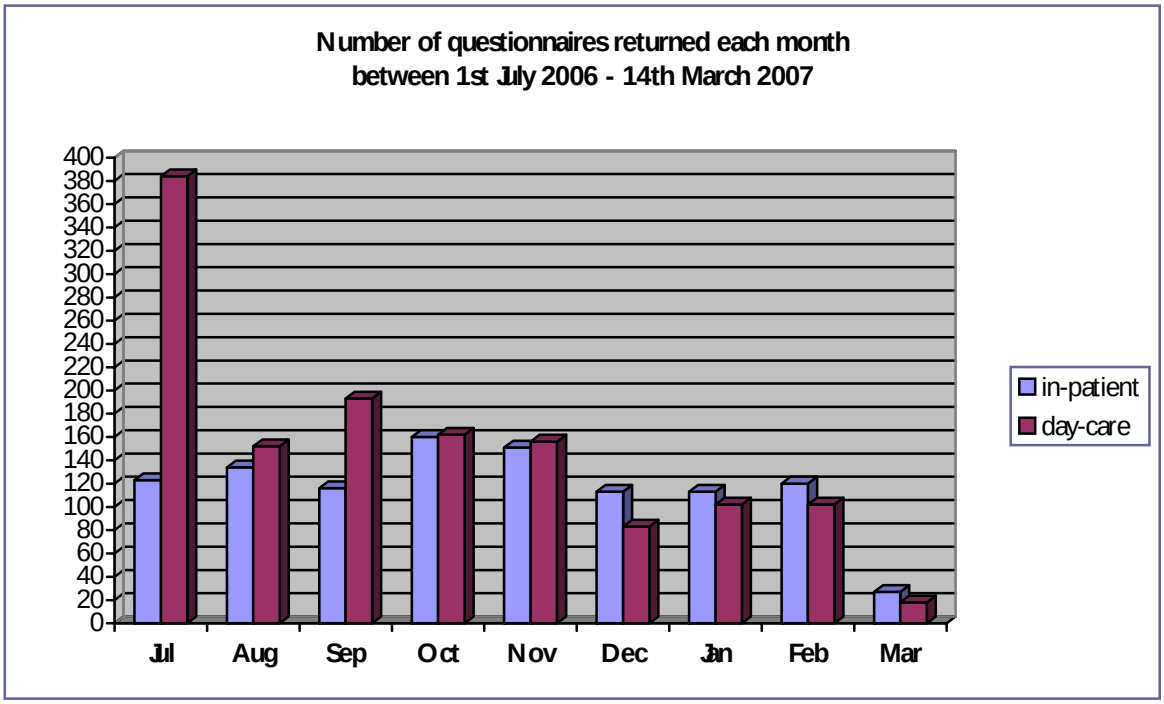
In preparation for the distribution of the survey each hospice was given a guidance sheet with detailed instructions of appropriate procedures, including start and end date, exclusion criteria, informing patients of the survey and how to return it. When distributing the questionnaires, hospice staff were asked to reassure patients that the survey is anonymous and the staff giving the care will not see the completed questionnaire. Patients were also told it would have no effect on their future care and were under no pressure to complete the survey.

Following experiences of the first patient survey the time frame for distribution and return of questionnaires was scheduled for eight months, between July 2006 and February 2007. A target of 40 completed questionnaires returned from one or both services was considered enough as a 'benchmark' figure. This figure was decided upon as in the 2004/05 reaching a response higher than 40 was difficult for the vast majority of hospices over the data collection period of six months. It was not compulsory for all the hospices taking part to reach the benchmark. Although it was encouraged for statistical reasons, the ability to achieve the benchmark depended on the size of the hospices involved. Hospices with more inpatients or users of daycare services would find it easier to achieve than hospices that were smaller in size.

The tables below show how the questionnaires were returned over the eight-month period. Questionnaires were accepted up until the middle of March to allow for return of questionnaires distributed in late February, at the end of the distribution period. The number of questionnaires returned was lower for inpatient services (1052)

compared to daycare services (1352), probably due to the lower number of patients using these services. However, the number of responses achieved for inpatients was higher compared to the 2004/05 survey and the number of responses from daycare services has decreased slightly. This is due to the slight difference in balance between the number of inpatient and daycare services taking part in the survey the second time around. The increase in inpatient returns could also be due to the increase in time allowed for data collection.





Overall the rate in which questionnaires were returned was steady for both service types, but returns from daycare units were particularly high during the first month of data collection in July. The high numbers and then

the decrease in returns is due to the reducing number of patients who fit the criteria, as over time there would less and less patients who hadn't already been asked to complete a questionnaire. For the actual numbers returned by individual participating hospices see Appendix D. Incomplete information fed back by a few of the participating hospices on the number of questionnaires distributed, indicate that the response rate for the survey appear to be quite high (50% or more).

The collected data was entered and analysed using SPSS v14 software (Statistical Package for the Social Sciences). Open ended and textual comments were entered and analysed separately using Excel.

4. Results: daycare

Results of the survey of daycare patients are given in the following sections:

4.1 Individual hospice daycare results
4.2 Benchmark daycare results (10 hospices)
4.3 Average daycare results overall (49 hospices)
4.4 Daycare textual comments (49 hospices)

4.1 Individual hospice daycare results

(Individual hospice results were included in the reports given to each participating hospice)

4.2 Benchmark daycare results (10 hospices)

Ten hospices reached the benchmark figure of 40 returned daycare questionnaires and are included in the benchmark results. This section of the report gives an overview of the average results of these hospices by presenting the results in tables, charts and in a written commentary of the findings for each area covered by the survey: provision of information about services, anxiety when first visiting daycare, use of transport, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on facilities and services.

The results, in table form, report the average patient responses from all ten hospices aggregated together. The range of aggregated results of the benchmark hospices is also reported, showing the result for the lowest average benchmark hospice and the result for the highest average benchmark hospice for each question. The average results displayed in these tables are then reported visually in a bar chart for each question.

The benchmark results for daycare are very similar to the 2004/05 survey and therefore any notable differences (of around -/+5% or more) are reported in the written commentary. However different groups of hospices reaching the benchmark in both surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. Fewer hospices achieved the daycare benchmark this year compared to last year when 13 hospices achieved the benchmark. Half of the hospices in this years benchmark results also achieved the daycare benchmark in the 2004/05 survey.

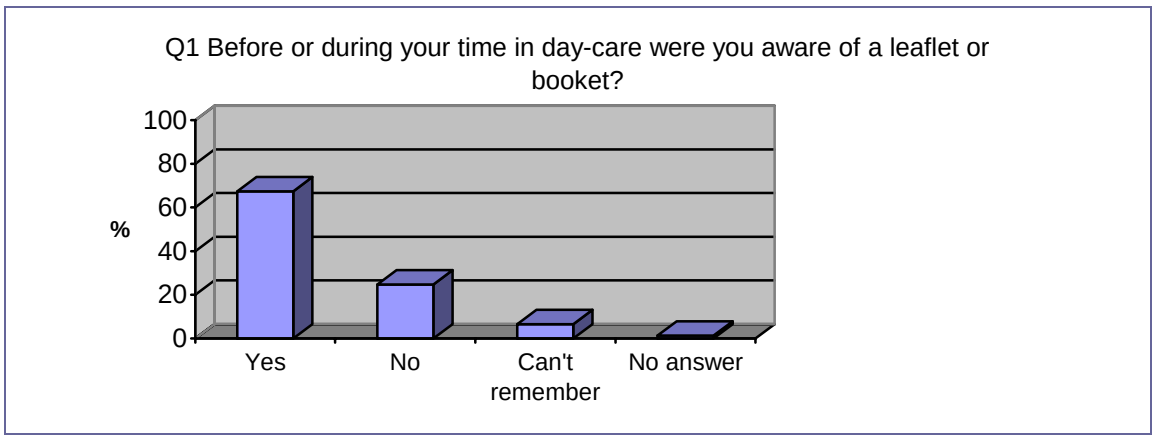
Provision of information about daycare services

In this year's survey all daycare patients were asked whether they were aware of an information leaflet or booklet on the services that their hospice provides. If a patient had looked at the leaflet, they were asked some follow up questions about whether they found the leaflet helpful, easy to understand, whether they found anything to be incorrect and whether they had any suggestions to make of other information that should be included in the leaflet.

The majority of the daycare patients (67%) said they were aware of an information leaflet or booklet. There was more awareness of such a leaflet or booklet in some of the benchmark hospices compared to others, eg nearly half indicated that they were not aware of such a leaflet or booklet in one of the hospices and in another a relatively high percentage (21%) said they couldn't remember if they were made aware of it or not. Of the respondents who were aware only three said they didn't actually look at the leaflet or booklet; a slightly higher percentage didn't answer the subsequent questions on this and so it is possible that these respondents hadn't looked at the leaflet or booklet either.

Q1Before or during your time in daycare were you aware of a leaflet or booklet?

	N	Average (%)	Range (%)
Yes	316	67.4	44.0 – 88.7
No	116	24.7	7.5 – 48.0
Can't remember	31	6.6	0.0 – 21.3
No answer	6	1.3	0.0 – 4.1
Total	621	100	

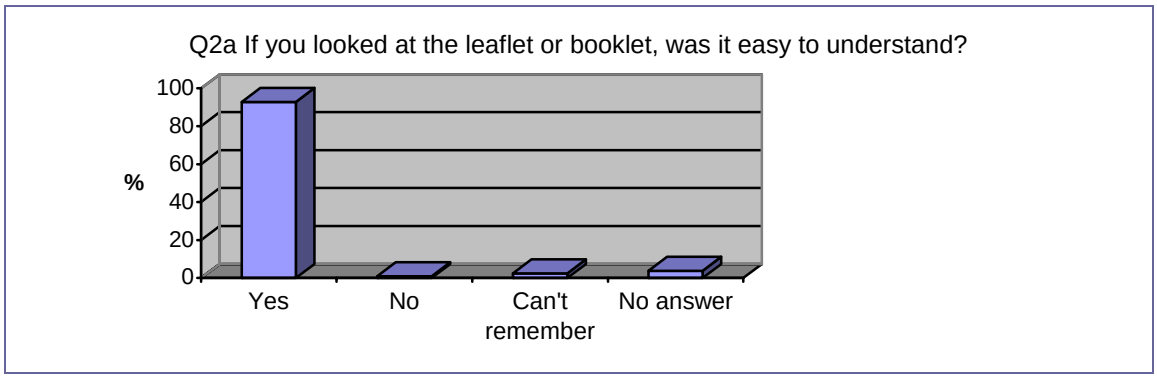


Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on daycare services, with the vast majority of patients who had looked at the leaflet reporting that it was easy to understand (93%) and that it included information that was helpful to them (93%) which was very similar to the previous survey. Only three patients (1%) felt it was not easy to understand.

The vast majority of patients (93%) who looked at the leaflet or booklet said they found that it was helpful; only two respondents (1%) found it to have been unhelpful.

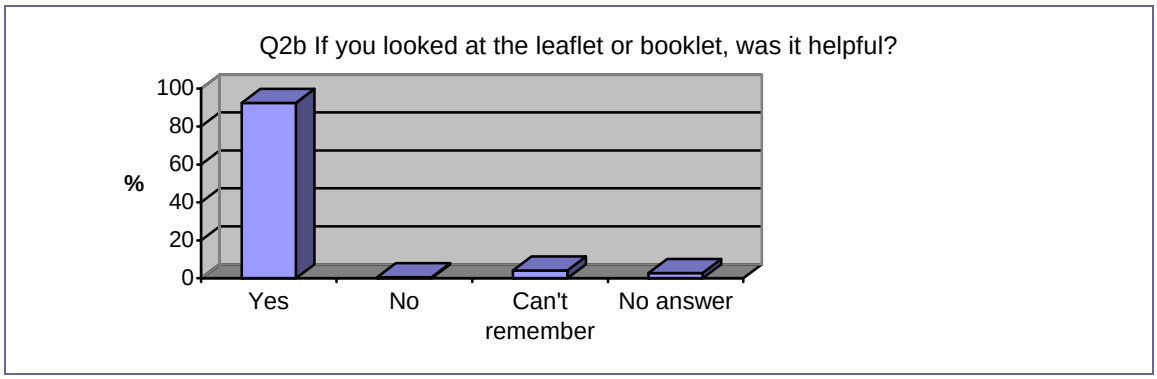
Q2a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)
Yes	296	92.8	86.2 – 97.1
No	3	0.9	0.0 – 4.3
Can't remember	8	2.5	0.0 – 5.9
No answer	12	3.8	0.0 – 10.3
Total	319	100	
Did not look at the leaflet or booklet: 3			
Not applicable: 147			



Q2b If you looked at the leaflet or booklet, was it helpful?

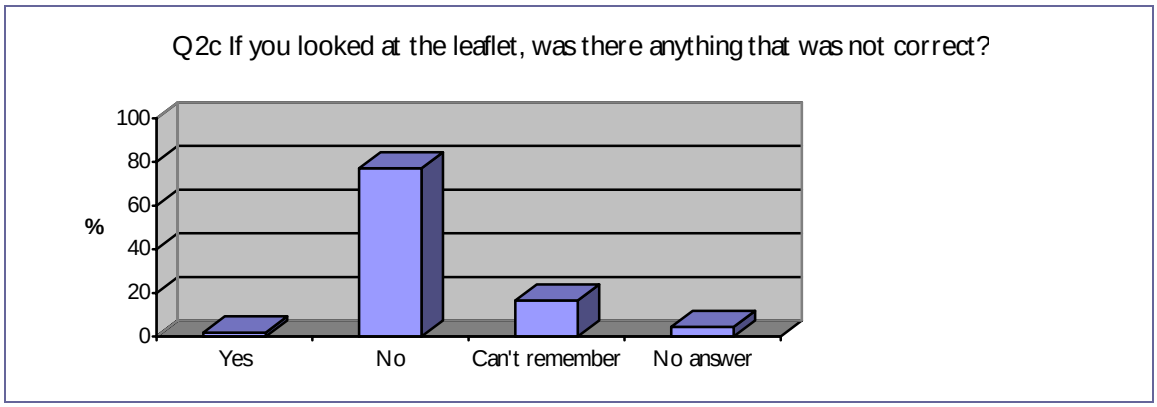
	N	Average (%)	Range (%)
Yes	295	92.5	79.3 - 100
No	2	0.6	0.0 – 4.3
Can't remember	13	4.1	0.0 – 13.8
No answer	9	2.8	0.0 – 6.9
Total	319	100	
Did not look at the leaflet or booklet: 3			
Not applicable: 147			



Only 2%, equating to six patients, said that they found something to be incorrect in the leaflet. However 17% said they couldn't remember if they found anything that was incorrect. Only 9% of patients who had looked at the leaflet (less than last year) had made a suggestion of others things that could be included in the leaflet. For comments on incorrect leaflets and suggestions of more information see the 4.4 textual comments section of this report.

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	6	1.9	0.0 – 4.3
No	246	77.1	58.6 – 94.1
Can't remember	53	16.6	3.1 – 37.9
No answer	14	4.4	0.0 – 11.8
Total	319	100	
Did not look at the leaflet or booklet: 3			
Not applicable: 147			

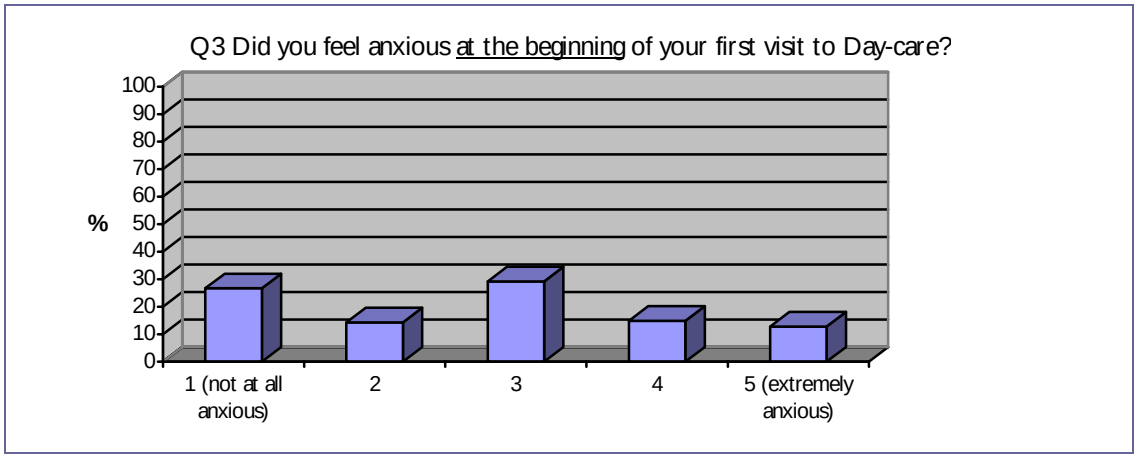


Anxiety on first daycare visit

Respondents were asked about how anxious they felt on their first visit to their daycare hospice. The questions asked were designed to measure the difference in anxiety felt at the beginning of their first visit compared to the anxiety they felt at the end of their first visit. The results show that levels of anxiety at the beginning of the first visit were generally low, with 27% of respondents reporting that they were not at all anxious (slightly lower than the 2004/05 survey). Answers for 29% of the respondents indicated that they felt neither 'anxious' nor 'not anxious' and 13% felt extremely anxious. Respondents were much less anxious at the end of their first visit, with 69% reporting that they were not anxious at all and only 2% reporting that they felt extremely anxious.

Q3 Did you feel anxious <u>at the beginning</u> of your first visit to daycare?

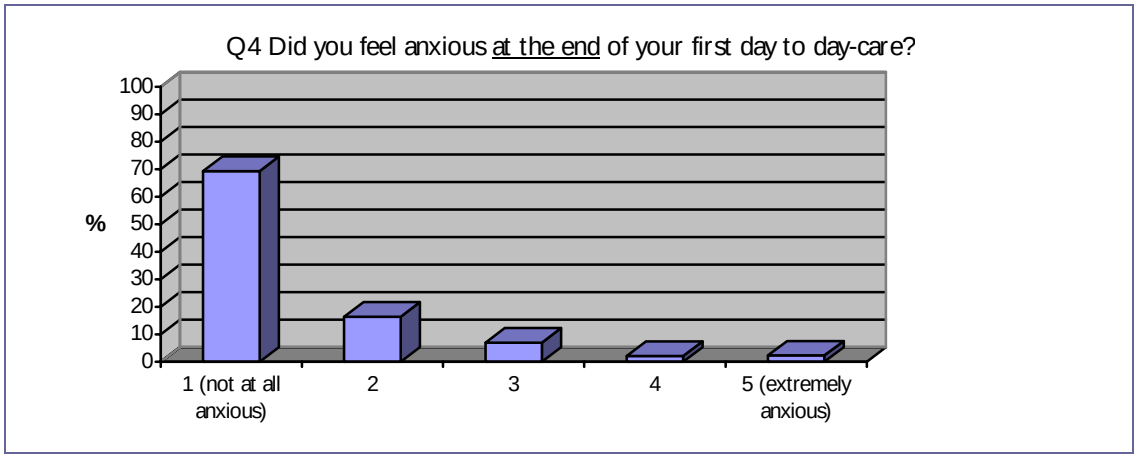
	N	Average (%)	Range (%)
1. Not at all anxious	125	26.7	17.0 – 42.5
2.	67	14.3	5.0 – 26.7
3.	137	29.2	14.9 – 40.4
4.	70	14.9	10.0 – 22.4
5. Extremely anxious	60	12.8	4.1 – 18.0
Can't remember	5	1.1	0.0 – 2.4
No answer	5	1.1	0.0 – 2.5
Total	469	100	



Q4 Did you feel anxious <u>at the end</u> of your first visit to Day care?

	N	Average (%)	Range (%)
1. Not at all anxious	325	69.3	58.5 – 82.2

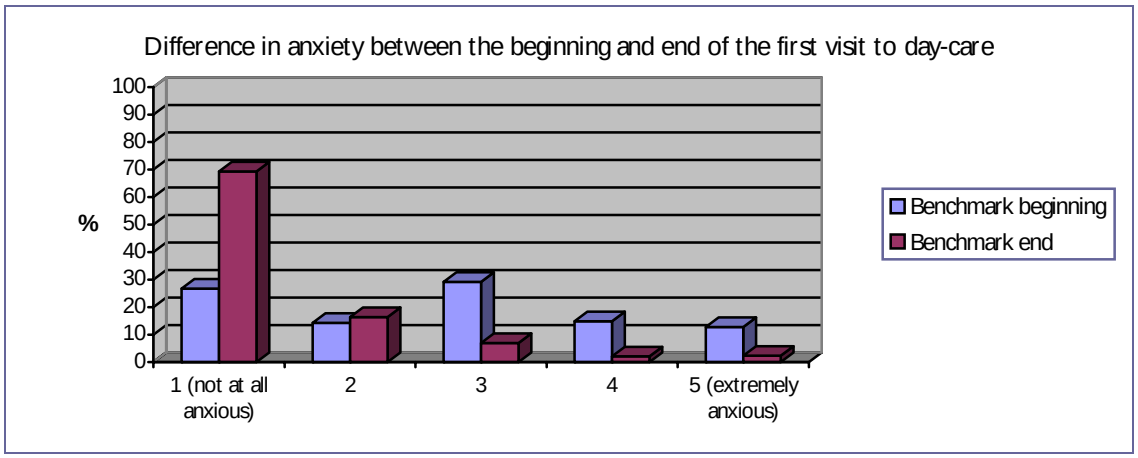
2.	77	16.4	11.5 – 20.8
3.	33	7.0	2.3 – 18.9
4.	10	2.1	0.0 - 6.4
5. Extremely anxious	11	2.3	0.0 – 5.0
Can't remember	1	0.2	0.0 – 2.4
No answer	12	2.6	0.0 – 7.5
Total	469	100	



When looking more closely at the change in anxiety from the beginning and end of the first visit unsurprisingly the change was towards more respondents becoming less anxious. There was a 65% change towards people being less anxious at the end of the visit compared to the beginning (a greater percentage than the 2004/05 survey). There was only a small change of 2% towards being more anxious at the end of the visit compared to the beginning. There was no change in anxiety for 33% of respondents and these were largely the group who would have felt 'not at all anxious' at the beginning of the visit. Therefore it is unsurprising that the proportion of 'no change' is lower compared to the previous survey given that patients in the latest survey were less anxious in the first place. Results on change in anxiety were not available for 18 respondents as they did not answer both of the questions on anxiety before and after their first visit to daycare. Respondents were invited to make suggestions of actions their hospice could have done to relieve their anxiety. These comments are presented in the 4.4 textual comments section of this report.

Change in anxiety between the beginning and end of the first visit to Daycare (Q3/4)

	N	Average (%)	Range (%)
Less anxious	291	64.5	48.6 – 72.1
No change	149	33.0	24.4 – 45.9
More anxious	11	2.4	0.0 – 6.4
Total	451	100	
Not applicable: 18			



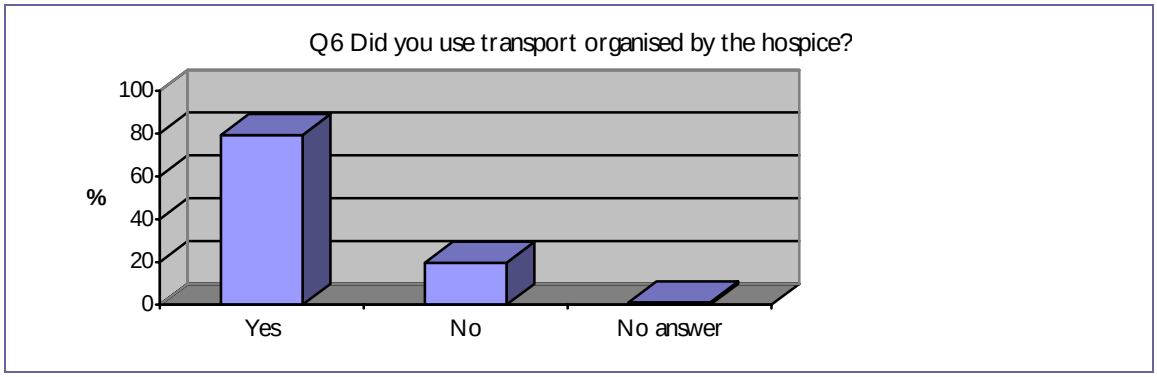
Use of transport by daycare patients

The majority of daycare patients overall (79%), ranging between 57% - 98%, have used transport organised by their hospice. As in the previous survey the majority who reported using transport organised by their hospice also reported the standard of this service to be excellent. 75% of those who had used the transport felt the promptness of pick up (ie whether they were picked up on time) was excellent compared to 4% who felt it was poor. Similarly, 76% felt the comfort of the journey was excellent compared to 5% who felt it was poor and 83% felt the safety aspects were excellent compared to 4% who felt it was poor.

It is in the aspect of safety where improvements on findings from the previous survey can be noticed, although the difference is small. The ranges reported below show that there was some variation in the views on hospice transport, but again the majority felt the service provided was excellent and few felt it was poor. Further comments made by respondents on hospice transport can be found in the 4.4 textual comments section of this report.

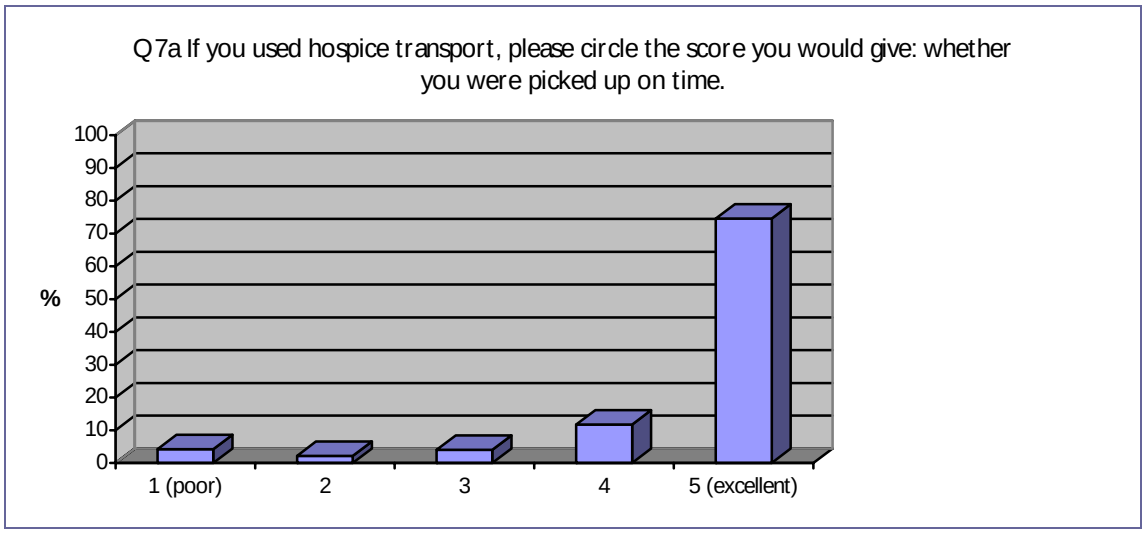
Q6 Did you use transport organised by the hospice?

	N	Average (%)	Range (%)
Yes	372	79.3	59.6 – 98.0
No	92	19.6	2.0 – 38.3
No answer	5	1.1	0.0 – 5.0
Total	469	100	



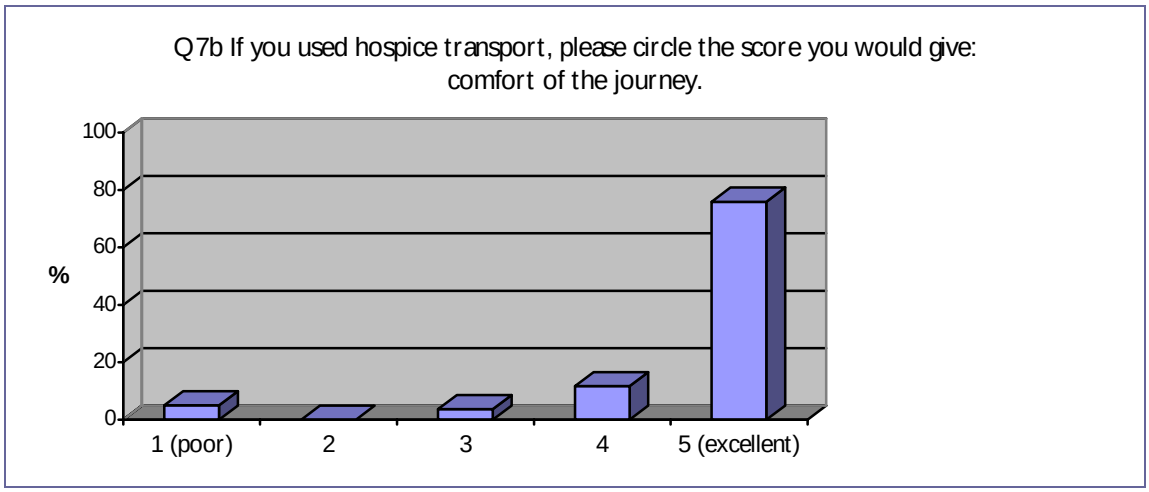
Q7a If you used hospice transport, please circle the score you would give: whether you were picked up on time.

	N	Average (%)	Range (%)
1. Poor	16	4.2	0.0 – 10.5
2.	8	2.1	0.0 – 5.4
3.	15	4.0	0.0 – 10.2
4.	44	11.7	3.8 – 20.9
5. Excellent	281	74.5	58.1 – 92.3
No answer	13	3.4	0.0 – 12.9
Total	377	100	
Not applicable: 92			



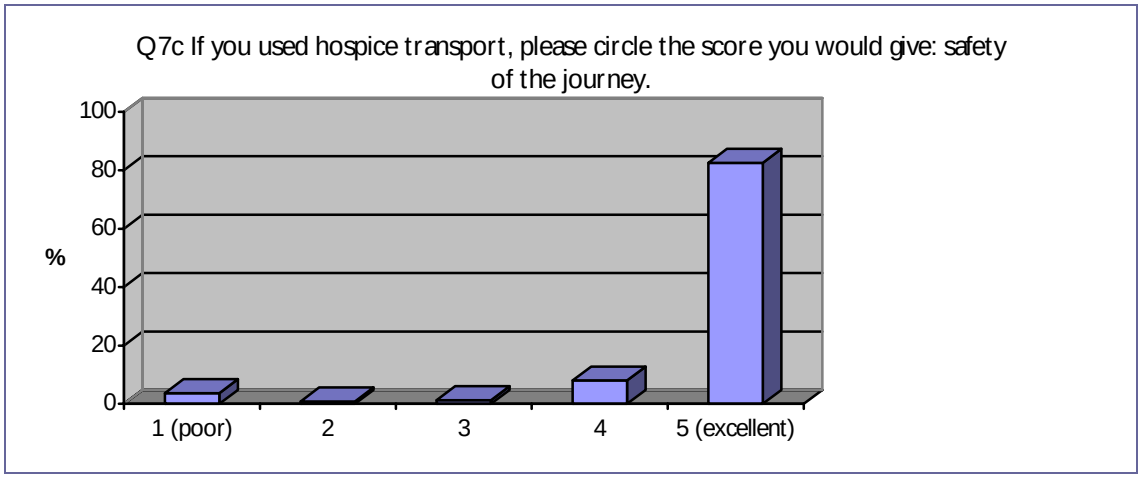
Q7b If you used hospice transport, please circle the score you would give: comfort of the journey

	N	Average (%)	Range (%)
1. Poor	19	5.0	0.0 – 10.8
2.	14	0.0	0.0 – 0.0
3.	44	3.7	0.0 – 7.9
4.	286	11.7	5.1 – 22.4
5. Excellent	377	75.9	67.4 – 84.6
No answer	14	3.7	0.0 – 12.9
Total	377	100	
Not applicable: 92			



Q7c If you used hospice transport, please circle the score you would give: safety of the journey

	N	Average (%)	Range (%)
1. Poor	14	3.7	0.0 – 10.3
2.	3	0.8	0.0 – 5.3
3.	5	1.3	0.0 – 5.4
4.	30	8.0	3.4 – 12.2
5. Excellent	311	82.5	74.4 – 92.3
No answer	14	3.7	0.0 – 12.9
Total	377	100	
Not applicable: 92			



Daycare staff: communication and care

The survey asked respondents about the communication and care they had received from staff in daycare. 85% of respondents reported that staff involved in their care always introduced themselves when they used the daycare services (this is a higher percentage to that reported in the previous survey, but the vast majority still said that staff had always introduced themselves). A further 12% said they introduced themselves most of the time and none of the respondents said that staff had never introduced themselves. As well as an introduction, staff are also regularly explaining what they were doing to patients when caring for them (slightly more so than in the previous survey). 77% reported that staff always explained what they were doing, 18% reported most of the time and none of the respondents reported that staff had never explained what they were doing. Respondents using daycare services were also asked whether they had confidence in the staff who were caring for them overall. The response to this question was very positive with 93% reporting that they always had confidence in the staff caring

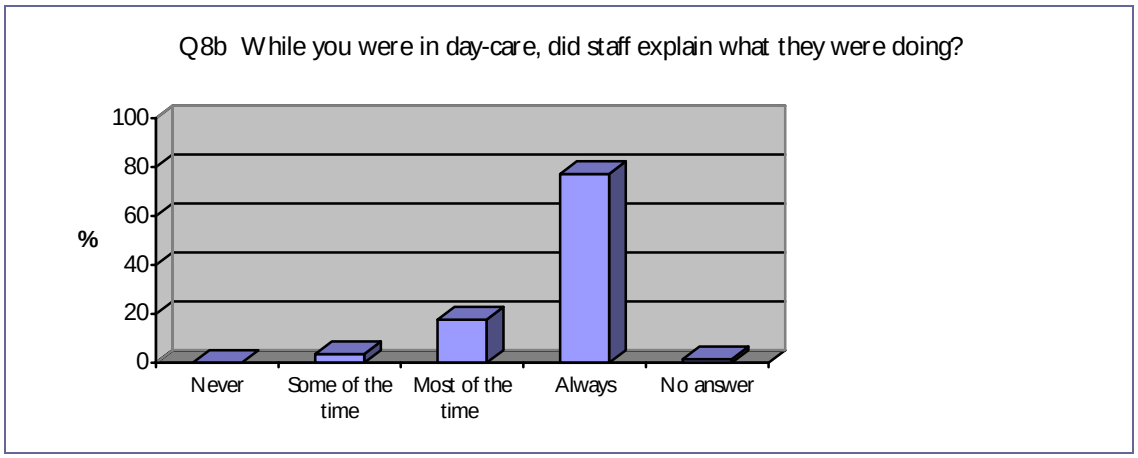
for them. None of the respondents felt that they 'never' had confidence in the staff, or only had confidence in them some of the time. Respondents were invited to make further comments on their confidence in staff, which can be found in the 4.4 textual comments section of this report.

Q8a. While you were in daycare, did staff involved in your care introduce themselves?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	6	1.3	0.0 – 7.5
Most of the time	54	11.5	4.0 – 18.4
Always	399	85.1	78.7 – 94.0
No answer	10	2.1	0.0 – 5.7
Total	469	100	

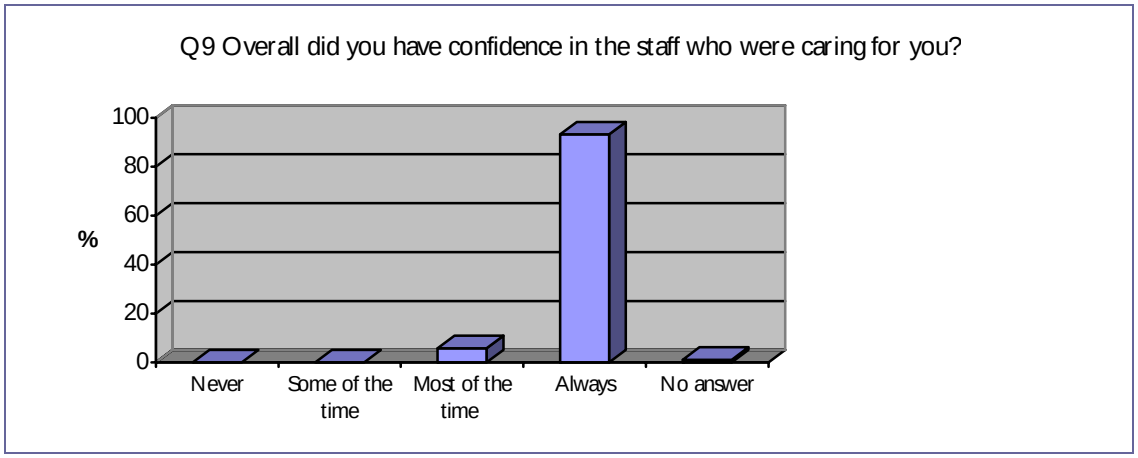
Q8b. While you were in daycare, did staff explain what they were doing?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	17	3.6	0.0 – 10.0
Most of the time	83	17.7	9.4 – 27.7
Always	362	77.2	61.7 – 88.7
No answer	7	1.5	0.0 – 4.3
Total	469	100	



Q9. Overall did you have confidence in the staff who were caring for you?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 - 0.0
Some of the time	0	0.0	0.0 – 0.0
Most of the time	27	5.8	2.0 – 10.2
Always	437	93.2	89.4 - 98.0
No answer	5	1.1	0.0 – 2.4
Total	469	100	

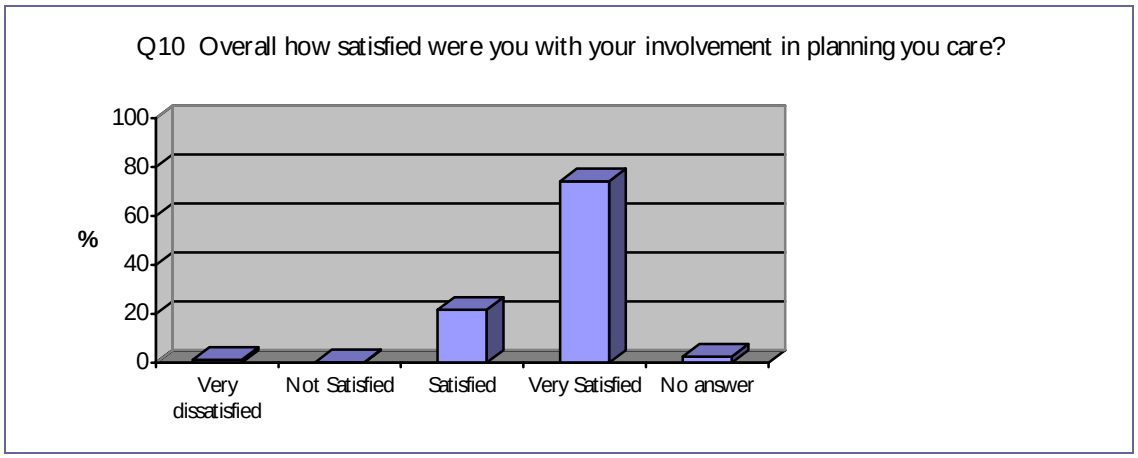


Daycare user involvement and understanding

Respondents were asked about their overall satisfaction with their involvement in the planning of their care while in daycare. Just under three quarters of respondents (74%) were very satisfied, which is a slightly higher percentage compared to the last survey. 22% were satisfied with the level of involvement in their care. Only 2% of respondents were either 'very dissatisfied' or 'not satisfied' with their involvement in their care. Of those who were either dissatisfied or very dissatisfied only 2 respondents made suggestions as to how their hospice could involve them more. For these suggestions of more information see the 4.4 textual comments sections of this report.

Q10 Overall how satisfied were you with your involvement in planning your care?

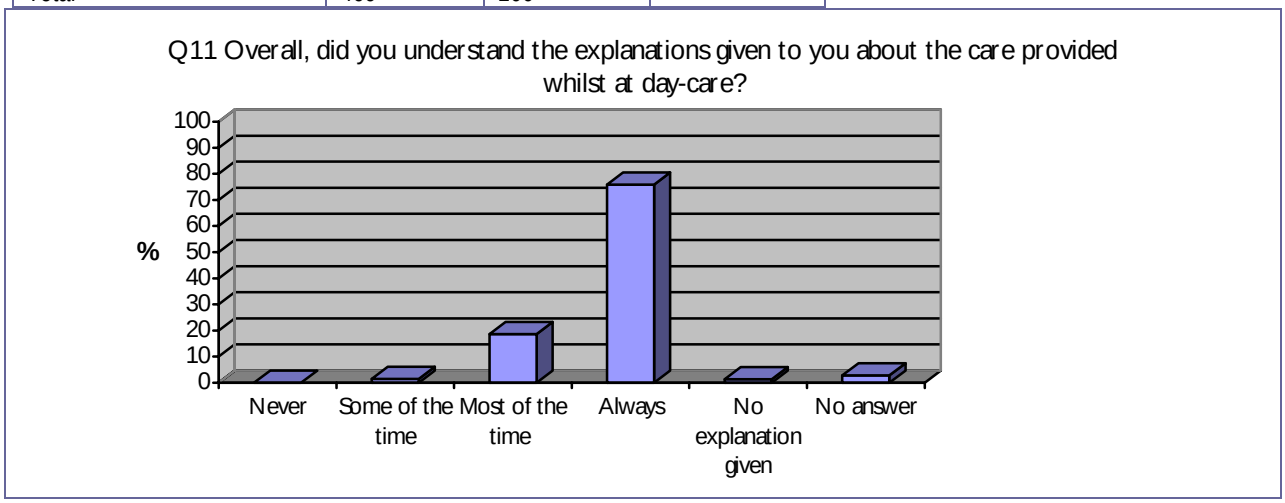
	N	Average (%)	Range (%)
Very dissatisfied	6	1.3	0.0 – 3.8
Not Satisfied	1	0.2	0.0 – 2.3
Satisfied	102	21.7	11.9 – 31.9
Very Satisfied	348	74.2	66.0 – 85.7
No answer	12	2.6	0.0 – 6.7
Total	469	100	



The survey also asked about users understanding of the explanations given to them about their care whilst in daycare. It is encouraging that the majority (76%) felt that they always understood the explanations given and 19% said they understood most of the time and no-one said that they never understood any of the explanations given to them. Only 5% of respondents suggested ways of making their hospice's explanations clearer. For suggestions see the 4.4 textual comments sections of this report.

Q11 Overall, did you understand the explanations given to you about the care provided whilst at daycare (this does not include the care provided by your GP or hospital)?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	7	1.5	0.0. – 4.4
Most of the time	87	18.6	9.6 – 34.0
Always	356	75.9	61.7 – 86.5
No explanation given	6	1.3	0.0 – 4.1
No answer	13	2.8	0.0 – 5.7
Total	469	100	



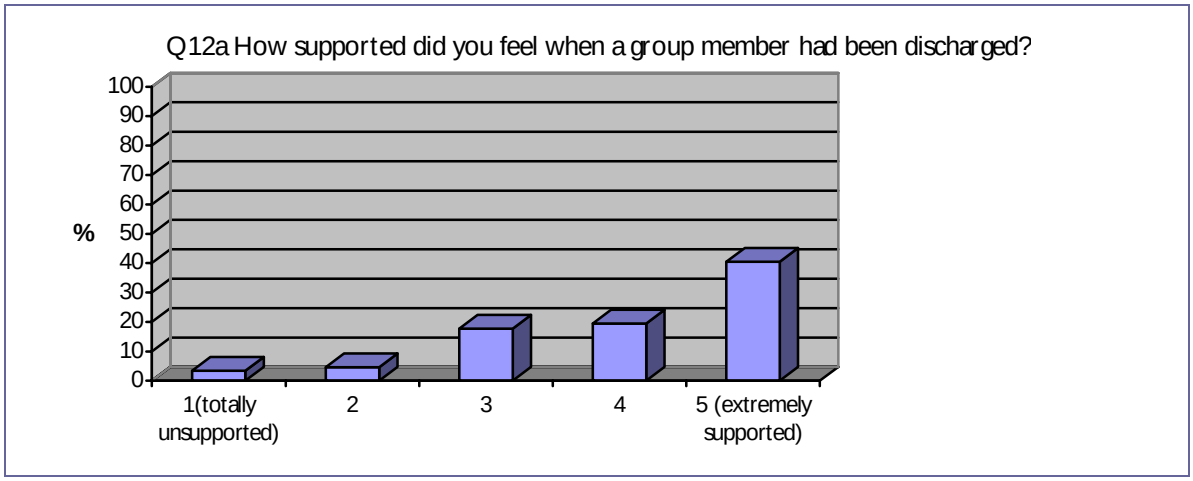
Views of users on the support and courtesy of daycare staff

A number of questions were asked in the survey about patient views on the support and courtesy of the staff looking after them in daycare. 41% of patients felt extremely supported when a group member had been discharged, compared to only 3% who felt totally unsupported. This question wasn't answered by 25-30% of respondents in some of the benchmark hospices, which may indicate a lower level of

certainty of support compared to other areas of care, also these percentages reflect the fact that half the respondents were not aware of anyone being discharged while they were at daycare. In comparison, more respondents felt support was given when a group member had died: 50% said they had felt extremely supported, but 5% felt totally unsupported (slightly higher than the rate when someone was discharged). These questions, on support when a patient had been discharged or had died, had the highest rate of non-completion compared to other questions in the survey.

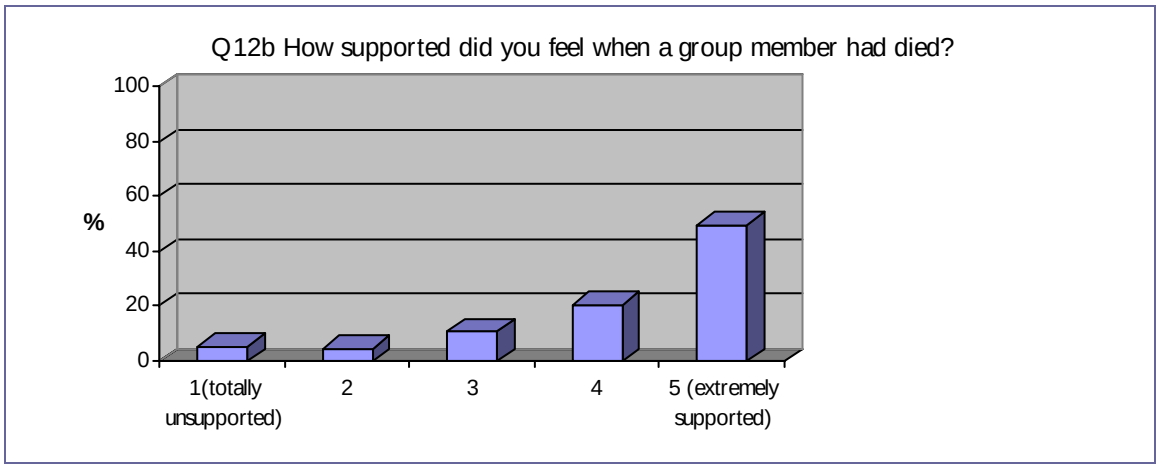
Q12a How supported did you feel when a group member had been discharged?

	N	Average (%)	Range (%)
1. Totally unsupported	8	3.4	0.0 - 15.4
2.	11	4.6	0.0 – 13.8
3.	42	17.7	10.0 – 25.0
4.	46	19.4	8.3 – 31.0
5. Extremely supported	96	40.5	25.0 – 57.9
No answer	34	14.3	3.4 – 30.0
Total	237	100	
Not applicable as no one had been discharged: 232			



Q12b How supported did you feel when a group member had died?

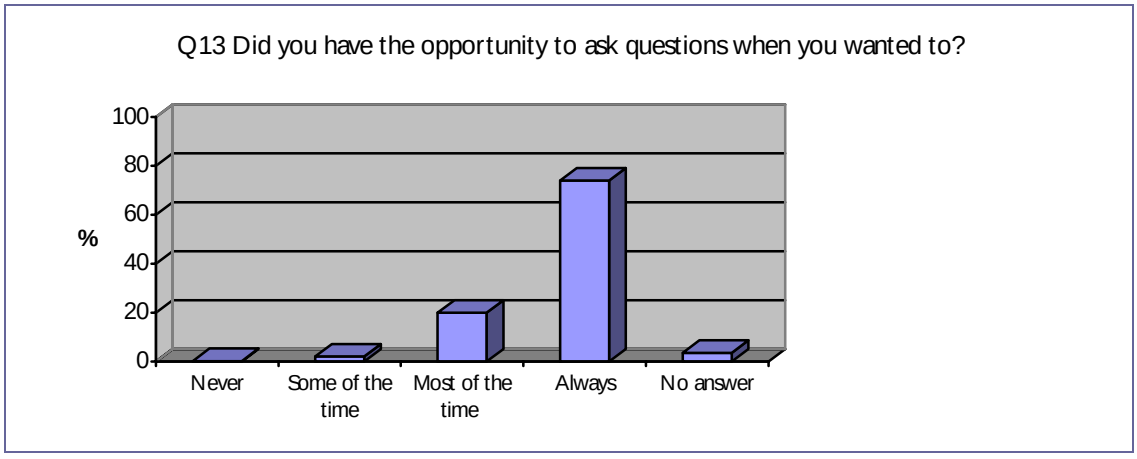
	N	Average (%)	Range (%)
1. Totally unsupported	16	5.4	0.0 – 10.5
2.	13	4.4	0.0 – 13.6
3.	32	10.9	0.0 – 22.7
4.	60	20.4	4.5 – 28.9
5. Extremely supported	146	49.7	30.8 – 66.7
No answer	27	9.2	3.3 – 16.7
Total	294	100	
Not applicable as no one had died: 175			



Respondents were more positive in their views on the support they received from staff more generally. 74% of respondent's felt that they were always given the opportunity to ask questions when they wanted to and 20% felt this to be true most of the time. 83% felt that staff always made an effort to meet their individual needs and wishes and 13% felt this most of the time.

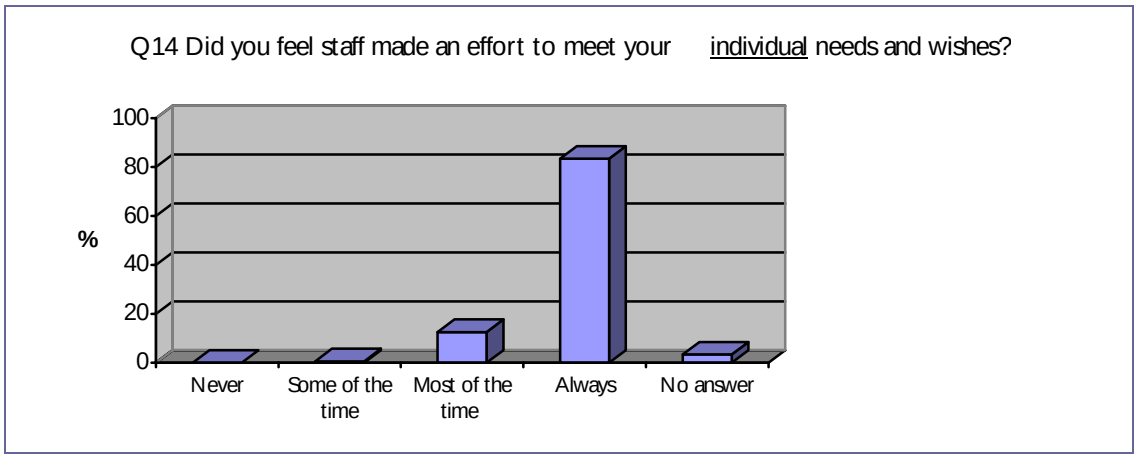
Q13 Did you have the opportunity to ask questions when you wanted to?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 1.9
Some of the time	10	2.1	0.0 – 6.4
Most of the time	94	20.0	12.5 – 31.9
Always	347	74.0	61.7 – 82.5
No answer	17	3.6	0.0 – 7.5
Total	469	100	



Q14 Did you feel staff made an effort to meet your individual needs and wishes?

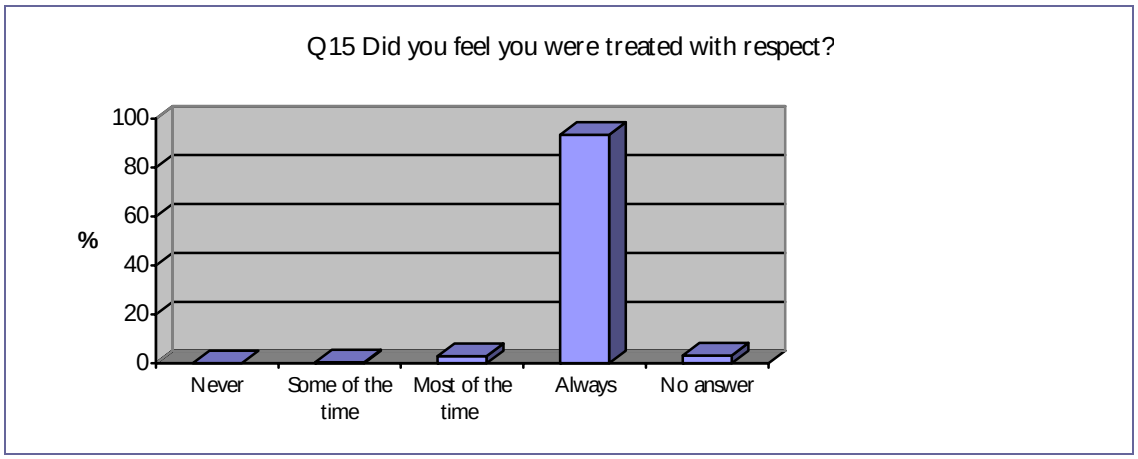
	N	Average (%)	Range (%)
Never	0	0	0.0 – 0.0
Some of the time	3	0.6	0.0 – 4.3
Most of the time	59	12.6	7.7 – 23.4
Always	391	83.4	76.6 – 90.4
No answer	16	3.4	0.0 – 7.5
Total	469	100	



93% of patients felt they were always treated with respect and 87% felt that their privacy was always respected, when being examined or during discussions with staff for example. This figure for respect in relation to privacy is slightly lower compared to the 2004/05 survey. No-one felt that they were not treated with respect, or that their privacy was not respected.

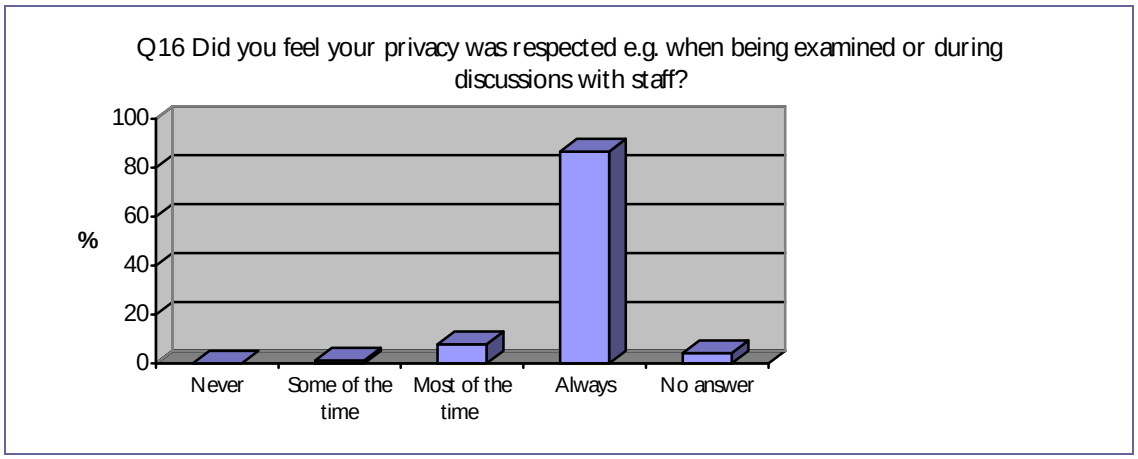
Q15 Did you feel you were treated with respect?

	N	Average (%)	Range (%)
Never	0	0	0.0 – 0.0
Some of the time	2	0.4	0.0 - 2.1
Most of the time	14	3.0	0.0 – 8.2
Always	438	93.4	87.8 - 100
No answer	15	3.2	0.0 – 7.5
Total	469	100	



Q16 Did you feel your privacy was respected , eg when being examined or during discussions with staff?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	6	1.3	0.0 – 4.3
Most of the time	37	7.9	0.0 – 16.3
Always	406	86.6	75.5 – 96.2
No answer	20	4.3	0.0 – 9.4
Total	469	100	



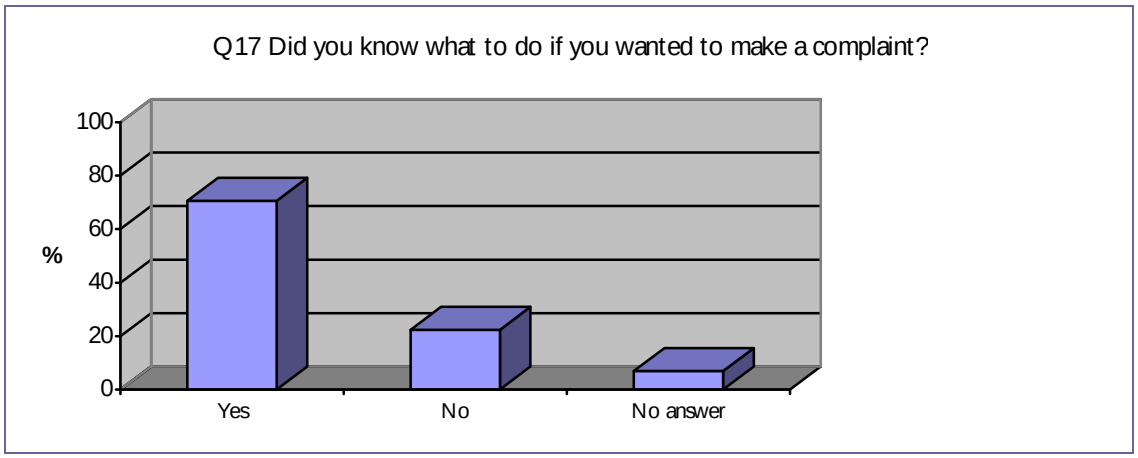
Daycare facilities and services

The type of facilities and services offered in daycare can vary greatly. This survey concentrated on general questions about facilities and services which would be applicable to all hospices. It asked about awareness of how to make a complaint, what they thought about the quality of the catering, the activities available, the number of staff and volunteers available when needed and also views on the daycare premise itself, by asking questions about the general environment/surroundings and the cleanliness of the building(s).

71% of respondents were aware of how to make a complaint compared to 22% who were not. Patients were slightly more aware of how to complain in this survey compared to the last survey. Awareness between the benchmark hospices did vary to a lesser degree this time (those aware ranged between 51% - 81%) and the majority of patients were aware of the procedures in place in all the benchmark hospices.

Q17 Did you know what to do if you wanted to make a complaint?

	N	Average (%)	Range (%)
Yes	331	70.6	51.1 – 80.9
No	105	22.4	11.5 – 40.4
No answer	33	7.0	2.0 – 15.6
Total	469	100	



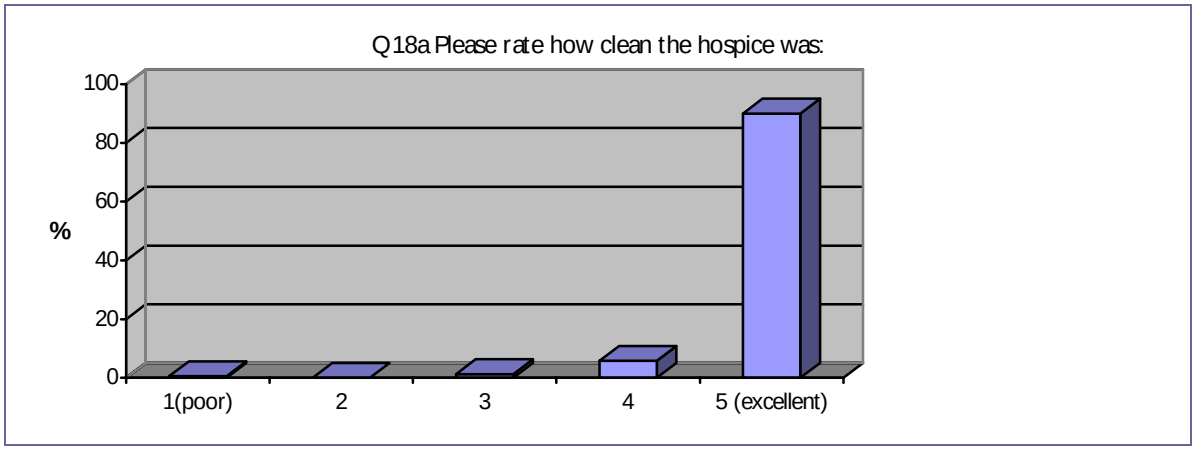
When asked to rate the following facilities and services they were viewed by the majority to be of a high standard and rated as excellent: how clean the hospice was (90%); the quality of the catering (68%); the activities available

to take part in (64%); and the general environment and surroundings (87%). Only between 1-2% felt that any of these facilities or services were poor. Although the majority were very happy with them, the quality of the catering and the activities available were the facilities patients were the least impressed with and there was great variations between the different benchmark hospices. The range of responses for rating the quality of the catering as excellent was between 38%-85%. Likewise, those rating the activities available to take part in as excellent ranged from 38%-83%. Comparing the rating of hospices facilities to the previous survey, the quality of the catering is the only area where the excellence rating has gone down.

Respondents were invited to make further comments on these facilities and services which can be found in the 4.4 textual comments section of this report. Regarding the number of staff and volunteers working in the respondent's hospice, the majority (81%) felt confident that there were enough staff and volunteers around to offer help if needed and 15% felt that there were enough most of the time.

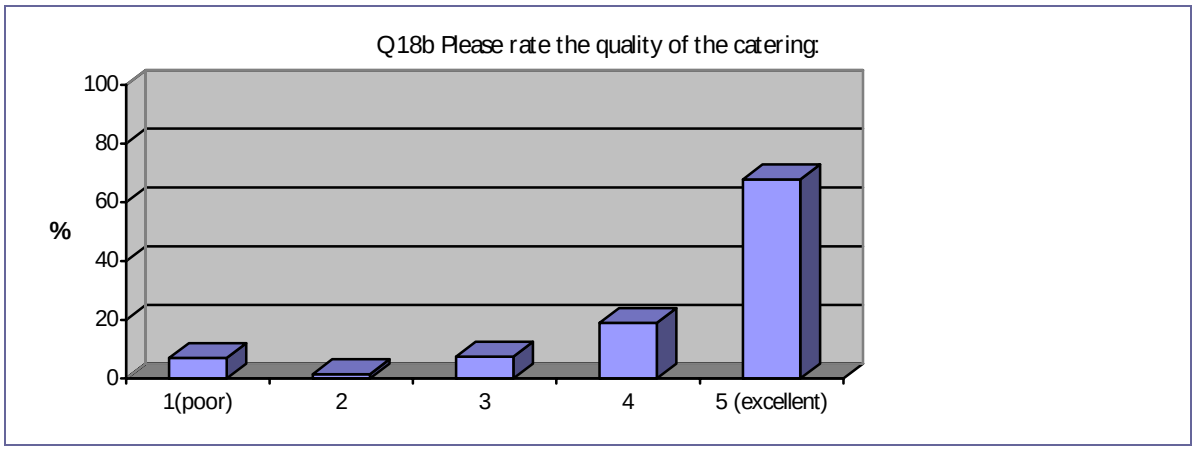
Q18a Please rate how clean the hospice was:

	N	Average (%)	Range (%)
1. Poor	3	0.6	0.0 – 2.5
2.	0	0.0	0.0 – 0.0
3.	6	1.3	0.0 – 4.0
4.	27	5.8	1.9 – 11.1
5. Excellent	422	90.0	86.7 – 93.6
No answer	11	2.3	0.0 – 5.0
Total	469	100	



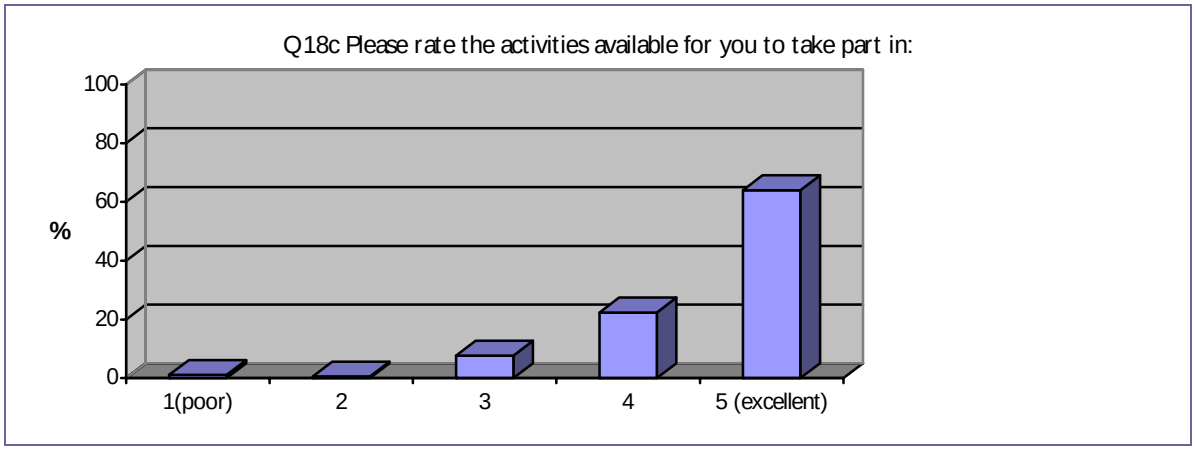
Q18b Please rate the quality of the catering:

	N	Average (%)	Range (%)
1. Poor	7	1.5	0.0 – 7.5
2.	6	1.3	0.0 – 11.3
3.	35	7.5	0.0 – 22.6
4.	89	19	6.4 – 34.0
5. Excellent	318	67.8	37.7 – 85.1
No answer	14	3	0.0 – 7.5
Total	469	100	



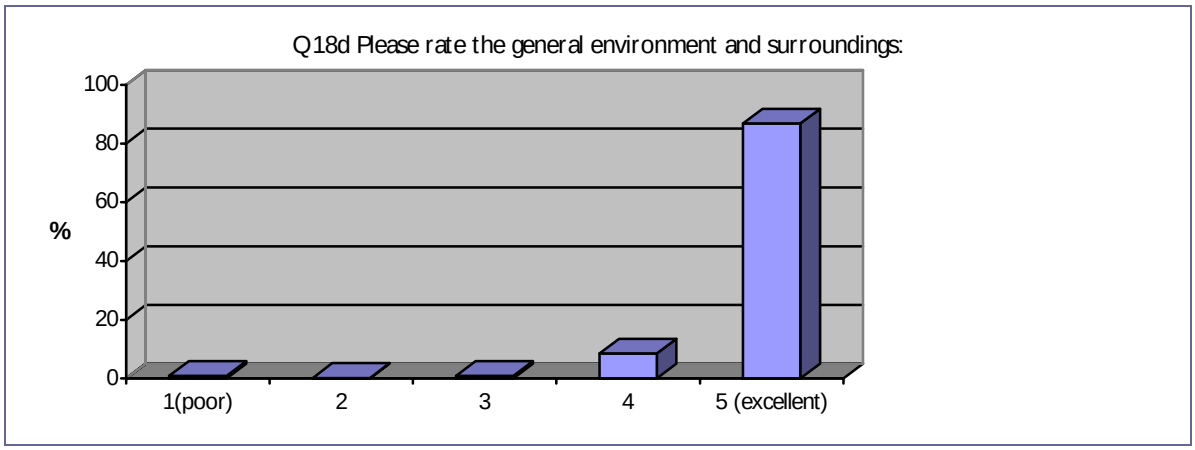
Q18c Please rate the activities available for you to take part in

	N	Average (%)	Range (%)
1. Poor	5	1.1	0.0 – 3.8
2.	3	0.6	0.0 – 2.0
3.	36	7.7	0.0 – 16.0
4.	105	22.4	11.5 – 38.0
5. Excellent	300	64.0	38.0 – 83.3
No answer	20	4.3	0.0 – 10.6
Total	469	100	



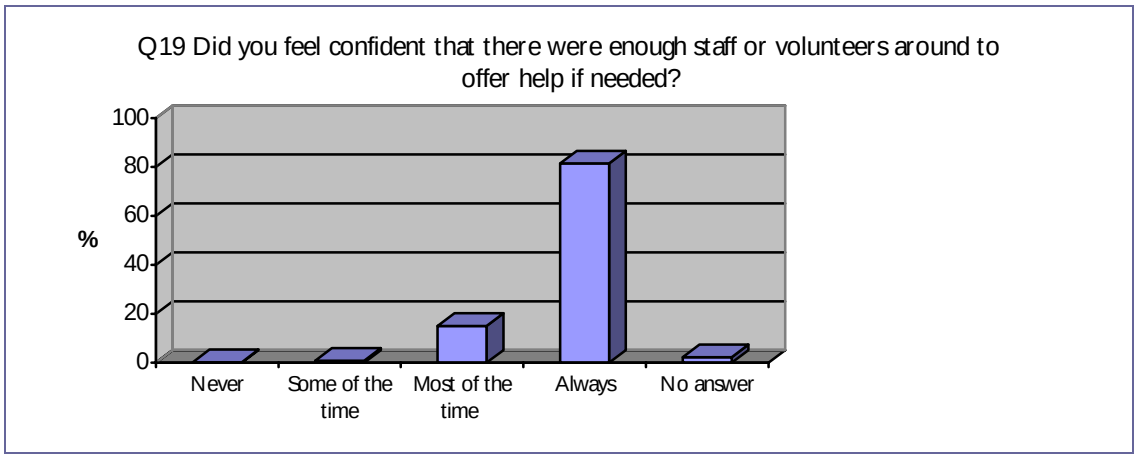
Q18d Please rate the general environment and surroundings:

	N	Average (%)	Range (%)
1. Poor	4	0.9	0.0 – 3.8
2.	1	0.2	0.0 – 2.1
3.	4	0.9	0.0 - 2.1
4.	40	8.5	0.0 – 16.0
5. Excellent	407	86.8	84.6 – 95.9
No answer	13	2.8	0.0 - 10.0
Total	469	100	



Q19 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.0
Some of the time	4	0.9	0.0 - 2.5
Most of the time	71	15.1	4.8 – 25.0
Always	382	81.4	67.5 – 92.9
No answer	11	2.3	0.0 - 5.7
Total	469	100	



4.3 Average daycare results overall (49 hospices)

The following results report the average responses of all participants aggregated together from all 49 hospices who took part in the daycare questionnaire. The total number of completed questionnaires received from daycare patients was 1352.

Service: Daycare N: 1352

Q1Before or during your time in daycare were you aware of an information leaflet or booklet?

Yes:	No	Can't remember	No answer
857 (63.4%)	378 (28.0%)	95 (7.0%)	22 (1.6%)

Q2a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
803 (93.0%)	4 (0.5%)	19 (2.2%)	37(4.3%)
Did not look at the leaflet or booklet: 16			
Not applicable: 473			

Q2b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
790 (91.5%)	6 (0.7%)	32 (3.7%)	35 (4.1%)
Did not look at the leaflet or booklet: 16			
Not applicable: 473			

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
15 (1.7%)	660 (76.5%)	136 (15.8%)	52 (6.0%)
Did not look at the leaflet of booklet: 16			
Not applicable: 473			

Q3 Did you feel anxious <u>at the beginning</u> of your first visit to daycare?

1 =Not at all anxious → 5 =Extremely anxious					Can't remember	No answer
1	2	3	4	5		
349 (25.8%)	214 (15.8%)	346 (25.6%)	190 (14.1%)	198 (14.6%)	17 (1.3%)	38 (2.8%)

Q4 Did you feel anxious <u>at the end</u> of your first visit to daycare?

1 =Not at all anxious → 5 =Extremely anxious					Can't remember	No answer
1	2	3	4	5		
923 (68.3%)	208 (15.4%)	94 (7.0%)	35 (2.6%)	32 (2.4%)	13 (1.0%)	47 (3.5%)

Change in anxiety between the beginning and end of the first visit to daycare (Q3/4)

Less anxious	No change	More anxious
827 (64.7%)	419 (32.8%)	32 (2.5%)
Not applicable: 74		

Q6 Did you use transport organised by the hospice?

Yes	No	No answer
990 (73.2%)	332 (24.6%)	30 (2.2%)

Q7 If you used transport, please circle the score you would give the following:

	1 =Poor → 5 =Excellent					No answer
	1	2	3	4	5	
Whether you were picked up on time	39 (3.8%)	18 (1.8%)	40 (3.9%)	124 (12.2%)	747 (73.2%)	52 (5.1%)
Comfort of journey	43 (4.2%)	10 (1.0%)	40 (3.9%)	135 (13.2%)	734 (72.0%)	58 (5.7%)
Safety of journey	40 (3.9%)	6 (0.6%)	17 (1.7%)	84 (8.2%)	820 (80.4%)	53 (5.2%)
Not applicable: 332						

Q8a While you were in daycare did staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	27 (2.0%)	161 (11.9%)	1135 (83.9%)	28 (2.1%)

Q8b While you were in daycare did staff explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
7 (0.5%)	50 (3.7%)	264 (19.5%)	1010 (74.7%)	21 (1.6%)

Q9 Overall did you have confidence in the staff who were caring for you?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	9 (0.7%)	81 (6.0%)	1246 (92.2%)	15 (1.1%)

Q10 Overall how satisfied were you with your involvement in planning your care?

Very dissatisfied	Not satisfied	Satisfied	Very satisfied	No answer
31 (2.3%)	11 (0.8%)	321 (23.7%)	947 (70.0%)	42 (3.1%)

Q11 Overall, did you understand the explanations given to you about the care provided whilst at daycare (this does not include the care provided by your GP or Hospital)?

Never	Some of the time	Most of the time	Always	No explanation given	No answer
2 (0.1%)	34 (2.5%)	251 (18.6%)	1001 (74.0%)	17 (1.3%)	47 (3.5%)

Q12a How supported did you feel when a group member had been discharged?

1 =Totally unsupported → 5=Extremely supported					No answer
1	2	3	4	5	
28 (4.0%)	42 (5.9%)	118 (16.7%)	136 (19.2%)	271 (38.3%)	112 (15.8%)
Not applicable as no one had been discharged: 645					

Q12b How supported did you feel when a group member had died?

1 =Totally unsupported → 5=Extremely supported					
1	2	3	4	5	No answer
53 (6.3%)	42 (5.0%)	110 (13.1%)	160 (19.0%)	389 (46.3%)	87 (10.3%)
Not applicable as no one had died: 511					

Q13 Did you have the opportunity to ask questions when you wanted to?

Never	Some of the time	Most of the time	Always	No answer
3 (0.2%)	39 (2.9%)	267 (19.7%)	993 (73.4%)	50 (3.7%)

Q14 Did you feel staff made an effort to meet your individual needs and wishes?

Never	Some of the time	Most of the time	Always	No answer
2 (0.1%)	15 (1.1%)	164 (12.1%)	1131 (83.7%)	40 (3.0%)

Q15 Did you feel you were treated with respect?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	6 (0.4%)	50 (3.7%)	1259 (93.1%)	36 (2.7%)

Q16 Did you feel your privacy was respected , eg when being examined or during discussions with staff?

Never	Some of the time	Most of the time	Always	No answer
2 (0.1%)	14 (1.0%)	98 (7.2%)	1187 (87.8%)	51 (3.8%)

Q17 Did you know what to do if you wanted to make a complaint?

Yes	No	No answer
953 (70.5%)	307 (22.7%)	92 (6.8%)

Q18 Please rate the following by circling your response:

	1 =Poor → 5 =Excellent					No answer
	1	2	3	4	5	
How clean the hospice was	19 (1.4%)	2 (0.1%)	16 (1.2%)	112 (8.3%)	1161 (85.9%)	42 (3.1%)
The quality of the catering	24 (1.8%)	10 (0.7%)	75 (5.5%)	226 (16.7%)	965 (71.4%)	52 (3.8%)
Activities available for you to take part in:	24 (1.8%)	31 (2.3%)	120 (8.9%)	302 (22.3%)	801 (59.2%)	74 (5.5%)
The general environment and surroundings:	17 (1.3%)	7 (0.5%)	21 (1.6%)	131 (9.7%)	1128 (83.4%)	48 (3.6%)

Q19 Did you feel confident that there were enough staff or volunteers around to offer help if needed?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	20 (1.5%)	210 (15.5%)	1077 (79.7%)	44 (3.3%)

4.4 Daycare textual comments (49 hospices)

Each hospice has been supplied with comments made by their patients in the individual hospice daycare results. This section summarises the comments from all hospices surveying daycare patients.

In the questionnaire there was room for respondents to write in additional remarks and clarifications. For example, to say in what way patients found information leaflets difficult to understand or unhelpful, or to elaborate on their 'ticked box' answers.

The greatest number of written comments were about the service generally (459 comments made) and about confidence in care staff (451 comments). Over 300 comments were also received in relation to hospice transport, relieving anxiety and the question on hospice cleanliness/ catering/ activities and environment. Many patients also made comments about the questionnaire (197 commented). In total 2403 comments were made by daycare patients.

While the responses were expected to identify areas where improvements might be made to the patient's experience, an overwhelming proportion of what patients wrote was positive and complimentary, showing how appreciative they were about many aspects of the care received. Only a fifth (21%) of the comments were ones that hospices could act upon and these are the main focus of the description of comments that follows. It should be noted that many of these are made by one or two people only.

Information leaflets (Q2)

A few comments were made about being unable to read the leaflet due to sight problems, one person said they found it difficult to read because of the layout with different font sizes, another said some terms like 'group member' were difficult to understand. They were not sure if this referred to their fellow patients or to the nursing staff.

Apart from the many positive comments, most comments were about the information included in leaflets. Patients wanted to know more about what to expect when they entered the hospice and what was available, eg the activities on offer, how often they run and the time they run. One patient felt that the leaflet gave the wrong impression that the therapies at their hospice were available more often than they actually were. Other patients felt that the leaflet should promote how beneficial hospice daycare is to try and dissolve any misconception about hospice care, which may 'put off' some people attending. A suggestion made by a few of the patients to help do this was for existing patients to write in the leaflet about their experiences and a 'typical day' in daycare. Another was to include photos so people could get a 'snapshot' of the daycare service.

There were a few practical comments like ensuring a leaflet went to GPs to inform them about daycare services as their GP was not aware and include information in the leaflet on directions to the hospice, opening times, how to book complementary therapies and other activities.

Relieving anxiety (Q5)

The great majority of comments were complimentary and a common theme was about their initial anxiety being dissipated:

> *'Any slight anxiety was immediately relieved by the warm and friendly reception I received and the facilities provided'*

> *'Everything was done day one to relieve my anxiety and was happy to stay after I'd met everyone'*

Reasons commonly given for anxiety before their first visit to daycare were fear of the unknown and feeling anxious meeting new people, particularly when there was a lot of people to meet in one go. One patient said it was difficult being the new person when everyone already knew each other *('everyone was very friendly but still it was like being a new school boy in school where everyone already knew each other''.* Another reason for initial anxiety was the stigma attached to the word 'hospice', whereby patients had a 'gloomy image' of what it would be like, which quickly disappeared when there.

Some patients felt they would have been less anxious if they had been given an information pack in advance or given the opportunity to have been shown around the day centre before their first visit, others said that doing this in advance had helped them. Some patients felt that having a staff member assigned to them or a 'mentor' on their first day to show them around and introduce them to others, or just someone to greet you when you arrived, would have helped *('to have a named person to greet me at reception and take we through to the centre*'). Some patients just felt that introduction of patients to new patients by staff and having the opportunity to talk to people would have been helpful. Having their carer, partner or son/daughter there on the first day did help, or would have helped, some patients. However, one patient commented that they weren't told that they were allowed to attend until after they had arrived.

Transport (Q7)

Again most of the comments were complimentary, such as, *'couldn't be faulted'*, *'excellent service' and 'all the drivers were friendly and helpful'.* Some said they were extremely grateful for the service otherwise they wouldn't be able to attend the hospice and some recognised that the drivers were volunteers and were appreciative.

Many patients said the drivers were punctual, but some said they were late-running, but understood it was because of the traffic. Other problems with hospice transport were that some vehicles were old and needed replacing, seats in smaller vehicles were less comfortable and harder to get in and out of and it felt safer in larger vehicles. Drivers speeding and braking suddenly didn't provide a very comfortable Journey for some patients on occasion. Some patients gave praise for drivers who helped them to get in and out of vehicles and made sure they got back in-doors safely. A couple of patients also commented that they would have liked to have been contacted if a driver couldn't turn up and vice versa, if anything happened and they couldn't attend patients would like a contact number to ring to let the driver know.

Care staff (Q9)

The question about confidence in the staff got the highest proportion of complimentary remarks, including:

> *'I look at the hospice as a loving family'*
>
> *I loved them all. They are all my special angels. I can't thank them enough'*
>
> *'The staff were more than helpful, they were more like a friend, nothing was too much trouble'*
>
> *'It is a comforting thought that so many people have my welfare at heart'*
>
> *'Through their support your life is made worth living'*

Generally patients found staff to be friendly, kind and caring, with knowledge of their condition. A few critical comments were that extra staff on duty would be helpful: one patient said that some excellent staff had to leave because of a lack of funding; another said that it would have been nice to have seen more staff during the day. Others thought it would be useful for patients to know the roles of the staff and for it was difficult to remember their names, a couple of patients suggested that they should wear name badges. In addition some patients said they would like to know which staff were on duty when they were there and who was absent; one patient said they felt lonely when key staff were away on holiday.

Care planning (Q10)

Some patients felt that they were not really involved in the planning of their care. Some said they were not aware that they could be involved in such planning. A few of the patients suggested that more communication and one-to-one sessions were sensible ways to increase involvement. Some patients would appreciate more involvement in their care plan as they had a complex or rare illness which staff were not so knowledgeable about. Some patients took the opportunity to mention other help they felt they needed or activities they would like to take part in, some examples were toe nails cutting, learn to play a musical instrument, more art materials needed.

Explanations about care (Q11)

Regarding explanations about care, quite a few patients commented on how clear explanations were or how well they understood them. Similarly some patients said they felt comfortable to ask again if they didn't understand the first time and the staff were happy to repeat information if needed. Some patients felt more information would be useful to make explanations clearer, but there was some mixed opinion as to how this should be done. Some thought one-to-one explanations were better while others favoured written explanations, a couple of patients also suggested more information should be give to their carers, spouse or to family. One patient suggested that perhaps 'a chat' every visit is better rather than patients having to ask to speak to staff.

Hospice cleanliness, catering, activities, general environment/surroundings (Q18)

These questions elicited many comments, most of which were complimentary, indicating how much patients valued the service provided and looked forward to their visit; for some it was the 'best day of the week'. Two patients wrote:

> *'It always seems to be a sunny, happy environment;, however gloomy or overburdened I feel on arrival I leave with a weight lifted and looking forward to next week'*
>
> *'I have felt welcome and cared for ever since I started to attend day care and the Queen herself could not get better attention'*

A couple of patients felt that the facilities at daycare provided them with quality time for themselves or their 'independence day'. Other complimentary comments were that the hospice was 'clean and tidy', 'like a hotel' has a 'wonderful aura' and the garden areas were particularly enjoyed. Some respondents were surprised at the good quality and variation of the catering, another described it as 'five star'.

In relation to comments where action could be taken, there was quite a mix of responses in this section. They included the following:

Activities – would like more activities generally and on the day they visit, as sometimes activities they wanted to do were not available for them on the day they attend. Suggestions for activities they wanted or particularly liked included: complementary therapies; physiotherapy; massage; reflexology; Reiki; making things for sale draw tickets; arts and crafts; organised games; exercise; swimming, activities more suited to men and to younger and older patients; inviting suggestions for activities; and more trips out. Some patients also said they were happy to pay towards trips out.

Premises – there were few critical comments on the cleanliness and the environment and surrounds of hospices. A few patients commented on the lack of cleanliness in the bathrooms, toilets or of furniture. Other patients mentioned the lack of space or poor layout in the hospice buildings, which was seen as disruptive or a lost opportunity for more activities in the hospice. Building work was mentioned and for some of these this was disruptive. Others included the hospice being too hot, not wheelchair friendly and hospice parking bays being occupied by those who shouldn't be using them.

Catering – some had problems with the choice of food on the menu, due to food sensitivities, being vegetarian, or they simply would have liked a greater choice and more variation. One patient felt sometimes the food choices were inappropriate: having a roast dinner on a hot day. There were a few comments on wanting better quality food, eg more fresh vegetables, vegetables being over cooked or under cooked and more sociability at meal times.

Overall comments (Q20)

Again many comments were written, most of which were very positive about the care received. Some commented that they couldn't see how the service could be improved, saying *'how can you improve excellent?'* and *'how can you improve on what we already have, the care and kindness is just amazing'*.

Patients continued to make remarks about activities, staff and the excellent service. Specific suggestions however were made about being able to attend daycare more frequently, increasing the number of staff, having more male volunteers, having more privacy and when speaking to a member of staff in confidence and the issue of hospice funding. Some patient said that they would be happy to contribute financially to meals, activities, outings and transport.

Another theme to note in particular, was how upset patients were when their time at daycare had to end. One person said they felt 'lost' when they could no longer attend. Another person said this was made easier for them as their hospice has arranged 'reunion days' so discharged patients could visit and see how their old friends were getting on.

The Questionnaire (Q21)

The majority of comments made about the questionnaire were positive, such as *'very easy to follow and answer'*, *'good selection of questions'*, '*good size of print*', *'clear and straightforward*'. Another patient wrote *'a difficult paper to compose for a cross response on this subject'*. This is an unusually positive response from people who have been asked to complete questionnaires.

Only a few patients thought the questionnaire was too long, one commented that it was 'heavy going' another that there were 'too many questions'. A few others found some questions to be unclear, too similar in content, not related to own circumstances, or could be simplified. On the other hand others felt it could have been more in depth and could have had more space to write personal views. One person felt that questionnaires were not an appropriate way to really understand the experiences and views of hospice patients: *'understanding impersonal on a subject so charged with emotion'*. A few patients suggested other topics that could be included, such as questions on various treatments and therapies and on the value of being a group member.

Overall the comments made about the questionnaire were positive, with some suggestions that can be used in future years.

5. Results: inpatient

The responses to the inpatient survey are given in sections as follows:

5.1 Individual hospice inpatient results
5.2 Benchmark inpatient results (9 hospices)
5.3 Average inpatient results overall (48 hospices)
5.4 Inpatient textual comments (48 hospices)

The inpatient questionnaire is in Appendix B

5.1 Individual hospice inpatient results

(Individual hospice results were included in the reports given to each participating hospice)

5.2 Benchmark inpatient results (9 hospices)

Nine hospices reached the benchmark of 40 returned inpatient questionnaires and are included in the benchmark results. This section of the report gives an overview of the average results of these nine hospices by presenting the results in tables, charts and a written commentary of the findings for each area covered by the survey: provision of information about services, staff communication and care, user involvement and understanding, views of users on support and respect they receive from staff, views on the facilities and services and users experience when calling for assistance.

The results, in table form, report the average of individuals from all nine hospices aggregated together. The range of aggregated results for all nine benchmark hospices is also reported, showing the result for the lowest average benchmark hospice and the result for the highest average benchmark hospice for each question. The average results displayed in these tables are then reported visually in a bar-chart for each question.

The benchmark results for inpatients are very similar to the 2004/05 survey and therefore any notable differences (of around -/+5% or more) are reported in the written commentary. However, different groups of hospices reaching the benchmark in both surveys make it difficult to interpret how meaningful such comparisons of similarities or differences are. More hospices achieved the inpatient benchmark this year compared to the last year when five hospices achieved the benchmark. Only two of the nine hospices in this years benchmark results also achieved the inpatient benchmark in the 2004/05 survey.

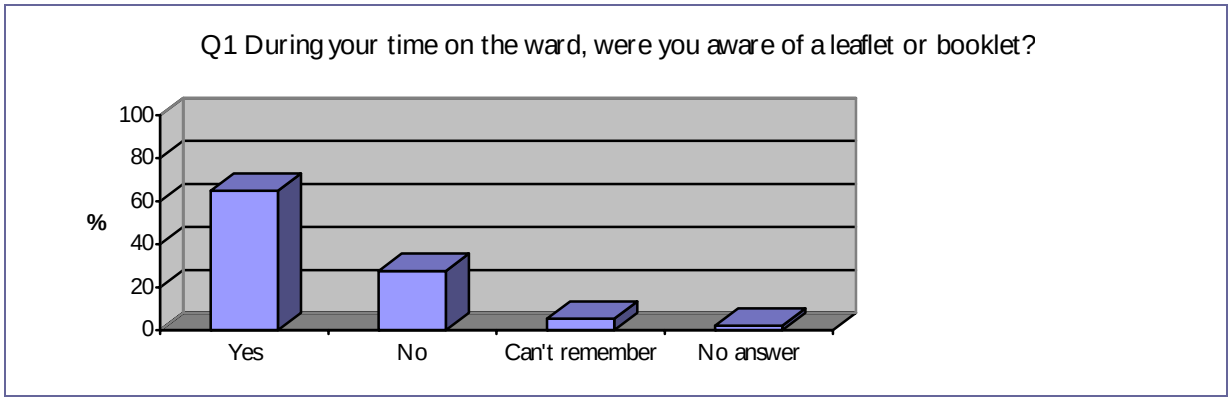
Provision of information about inpatient services

In this years survey inpatients were asked whether they were aware of an information leaflet or booklet on the services that their hospice provides. If a patient had looked at the leaflet, they were asked some follow up questions about whether they found the leaflet helpful, easy to understand, whether they found anything to be incorrect and whether they had any suggestions to make of other information that should be included in the leaflet.

Just under two thirds (65%) of inpatients were aware of the information leaflet or booklet. Awareness of the leaflet varied considerably between benchmark hospices (range: 43% - 81%).

Q1During your time on the ward, were you aware of a leaflet or booklet?

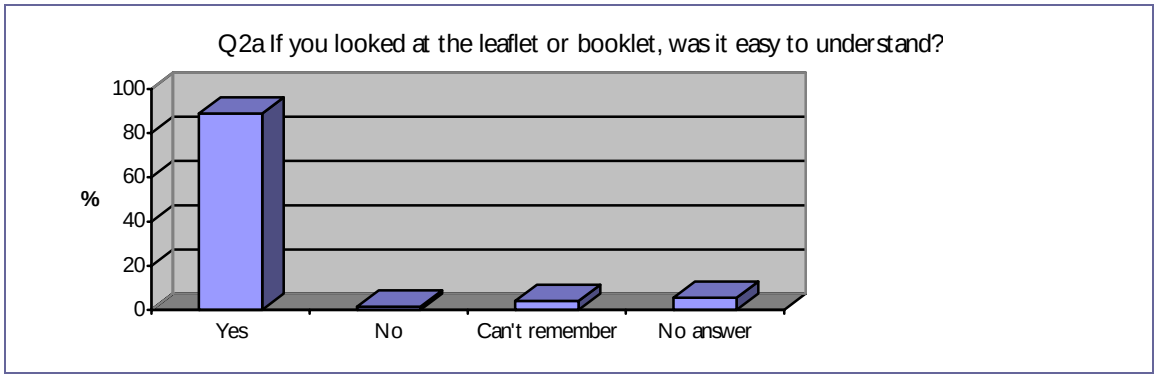
	N	Average (%)	Range (%)
Yes	275	64.9	42.6 – 80.7
No	117	27.6	12.3 – 46.6
Can't remember	23	5.4	1.7 – 17.0
No answer	9	2.1	0.0 - 4.7
Total	424	100	



Overall patients appear to be very satisfied with the content and user-friendliness of the leaflets on inpatient services, with the majority of patients who had looked at the leaflet reporting that it was easy to understand (89%); this is lower than the previous survey but a higher proportion (10%) either said they couldn't remember or did not answer the question. Only four patients felt that the leaflet wasn't easy to understand.

Q2a If you looked at the leaflet or booklet, was it easy to understand?

	N	Average (%)	Range (%)
Yes	239	88.8	77.3 – 95.5
No	4	1.5	0.0 – 6.9
Can't remember	11	4.1	0.0 – 6.9
No answer	15	5.6	0.0 – 18.2
Total	269	100	
Did not look at the leaflet or booklet: 15			
Not applicable: 140			

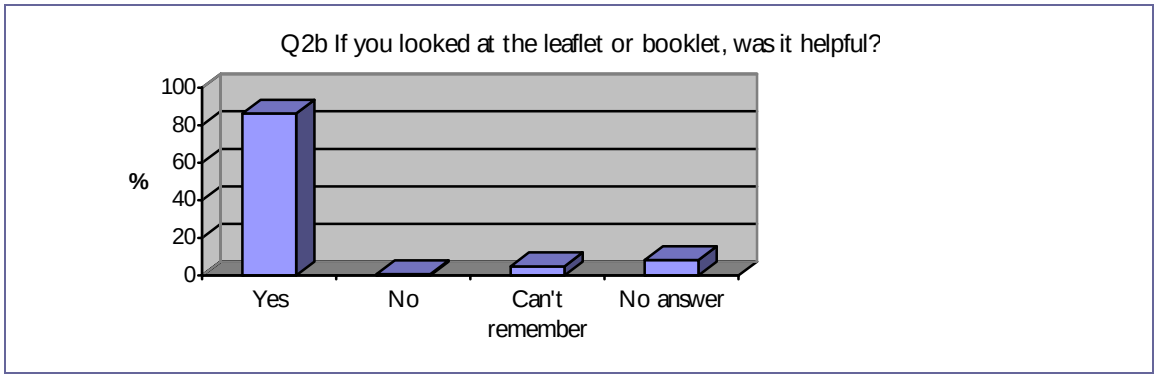


Patients also felt that the leaflet included information that was helpful to them (86%). Again this is slightly lower than last year, with a slightly higher proportion (8%) not answering the question. Only 4% (10 patients) said that they found something to be incorrect in the leaflet and only 6% of patients who had looked at the leaflet had made

a suggestion for including further or different information. For suggestions of more information see the 5.4 textual comments section of this report.

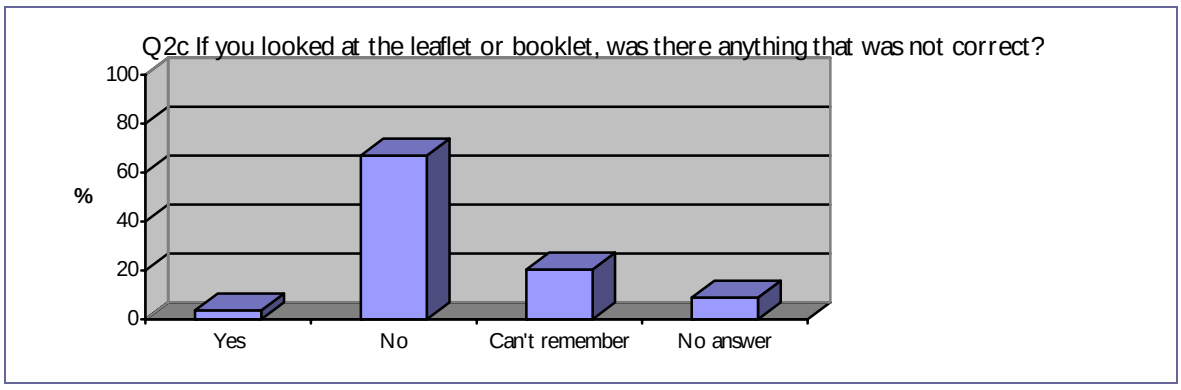
Q2b If you looked at the leaflet or booklet, was it helpful?

	N	Average (%)	Range (%)
Yes	232	86.2	72.7 – 94.7
No	2	0.7	0.0 – 3.7
Can't remember	13	4.8	0.0 – 13.6
No answer	22	8.2	0.0 – 13.6
Total	269	100	
Did not look at the leaflet or booklet: 15			
Not applicable: 140			



Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

	N	Average (%)	Range (%)
Yes	10	3.7	0.0 – 18.2
No	180	66.9	45.5 – 79.4
Can't remember	55	2.4	0.0 – 12.1
No answer	24	8.9	7.4 – 42.1
Total	269	100	
Did not look at the leaflet or booklet: 15			
Not applicable: 140			



Inpatient staff communication and care

The survey asked inpatients about the communication and care they had received from staff on the ward. The majority (73%) of respondents reported that staff involved in their care always introduced themselves. A further 19% said they introduced themselves most of the time and only two patients reported that staff had never

introduced themselves. Looking at the range of results, the proportion of staff always introducing themselves was more varied between hospices compared to the previous survey (60%-86%).

Q3a. While you were an inpatient, did staff involved in your care introduce themselves?

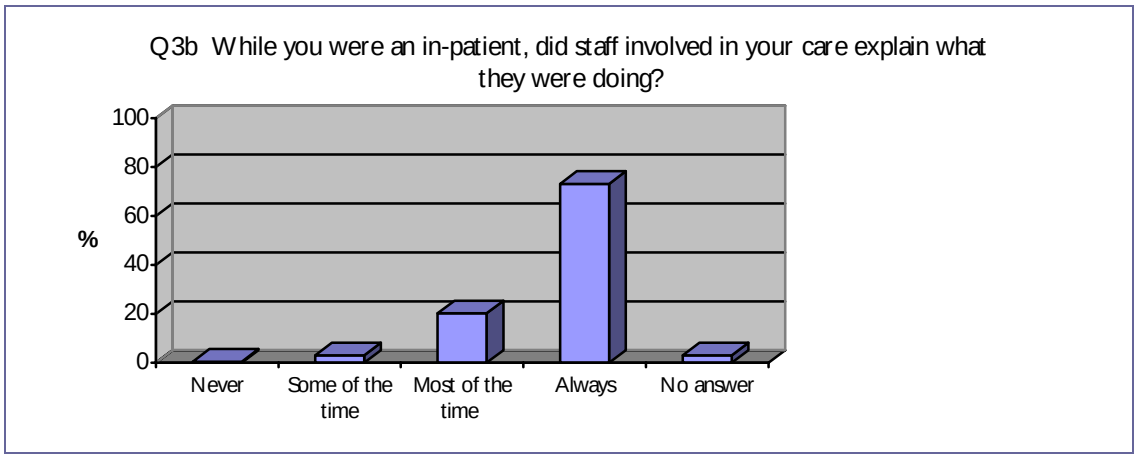
	N	Average (%)	Range (%)
Never	2	0.5	0.0 – 2.3
Some of the time	20	4.7	0.0 – 10.6
Most of the time	79	18.6	10.9 – 26.2
Always	308	72.6	59.6 – 86.4
No answer	15	3.5	0.0 – 8.5
Total	424	100	

As well as introducing themselves, staff frequently explained to patients what they were doing when caring for them. 73% reported that staff always explained what they were doing, 20% reported most of the time and only two patients reported that staff had never explained what they were doing. The range of responses from patients in hospices who always felt staff explained what they were doing was more varied this year compared to the last (60%-89%)

Inpatients were also asked whether they had confidence in the staff who were caring for them overall. The response was very positive with 81% reporting this always to be the case and 16% most of the time. Respondents were invited to make further comments on their confidence in staff, which can be found in the 5.4 textual comments section of this report.

Q3b. While you were an inpatient, did staff involved in your care explain what they were doing?

	N	Average (%)	Range (%)
Never	2	0.5	0.0. – 2.3
Some of the time	13	3.1	0.0 – 6.5
Most of the time	86	20.3	10.5 – 30.2
Always	310	73.1	59.6 – 88.6
No answer	13	3.1	0.0 – 8.5
Total	424	100	



Q4. Overall, did you have confidence in the staff who were caring for you?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.1
Some of the time	2	0.5	0.0 – 4.8
Most of the time	68	16.0	8.8 – 21.7
Always	344	81.1	73.9 – 86.0
No answer	9	2.1	0.0 – 5.3
Total	424	100	

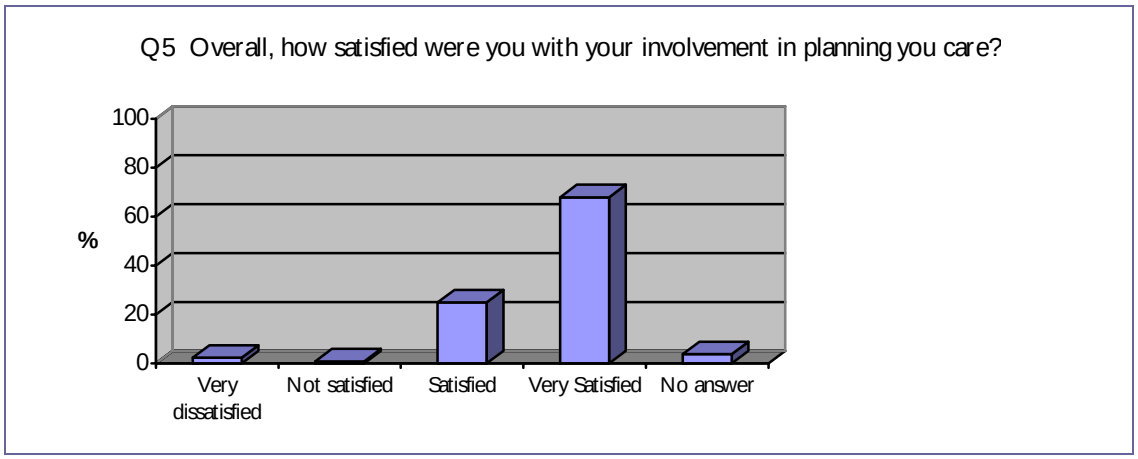
Inpatient involvement and understanding

Respondents were asked about their overall satisfaction with their involvement in the planning of their care while on the ward as an inpatient. 68% of respondents were very satisfied and 25% were satisfied with the level of involvement in their care. There is slightly lower proportion of satisfaction compared to the last year's survey. However a higher proportion (4%) didn't answer the question this year. Only a small proportion was either dissatisfied or very dissatisfied. These respondents were given the opportunity to suggest how they could be involved more in the planning of their care. For these suggestions of more information see the 5.4 textual comments section of this report.

Q5 Overall, how satisfied were you with your involvement in planning your care?

	N	Average (%)	Range (%)

Very dissatisfied	10	2.4	0.0 -7.1
Not satisfied	4	0.9	0.0 – 2.3
Satisfied	106	25.0	10.5 – 33.3
Very Satisfied	288	67.9	57.1 – 82.5
No answer	16	3.8	1.7 – 6.8
Total	424	100	

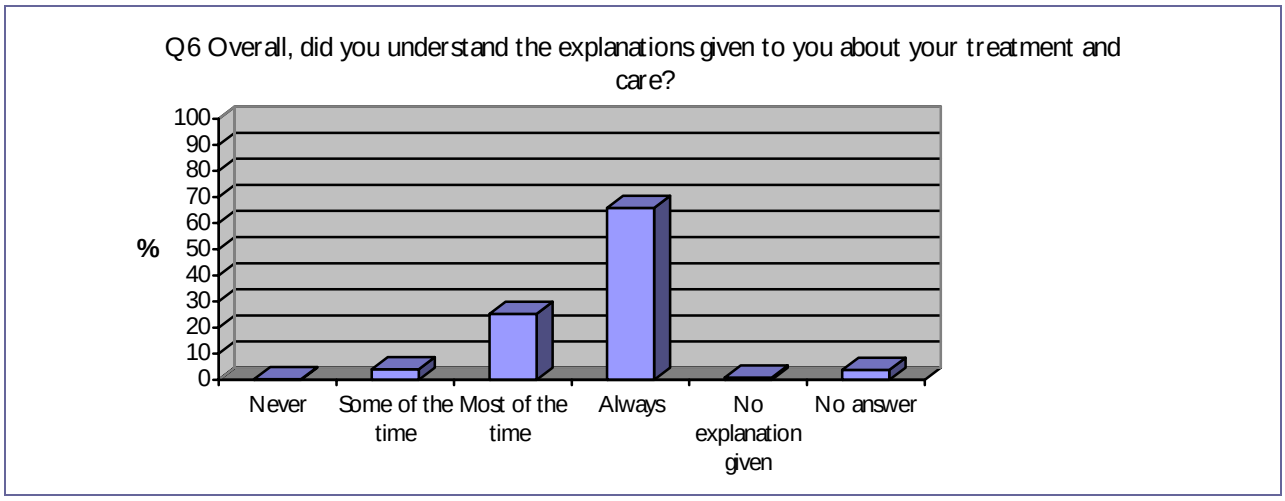


The survey also asked about users understanding of the explanations given to them about their care whilst on the ward. 66% of respondents (slightly higher than the last survey) felt that they always understood the explanations given to them and 25% said they understood most of the time. Only 8% of respondents suggested ways of making their hospice's explanations clearer. (for suggestions see the 5.4 textual comments sections in this report). Three quarters of the inpatients (75%) felt that they were always given the opportunity to ask questions when they want to and the opportunity was given most of the time to 18%, which is useful if an explanation isn't understood. The proportion who always felt they were given the opportunity to ask questions is less compared to the previous survey.

The majority of inpatient (more so than the previous survey) felt they were given the time they needed to make decisions regarding their care, 67% felt that they were always given enough time to make a decision and 24% felt they had enough time most of the time. The patient's experience of always having enough time for decision making was varied among the individual benchmark hospices (range: 55%-89%).

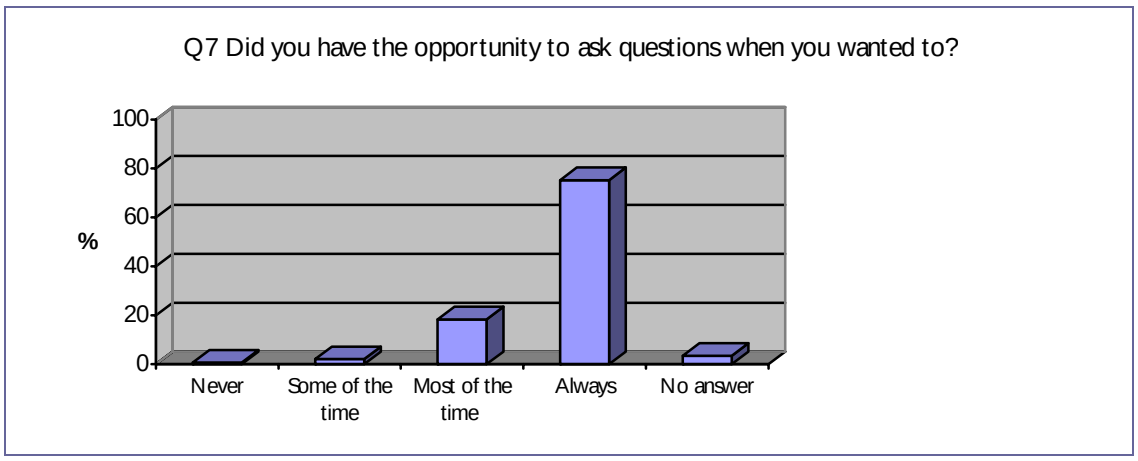
Q6 Overall, did you understand the explanations given to you about your treatment and care?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.1
Some of the time	17	4.0	0.0 – 10.9
Most of the time	107	25.2	15.2 – 34.1
Always	279	65.8	60.5 – 73.7
No explanation given	4	0.9	0.0 – 6.5
No answer	16	3.8	1.7 – 6.8
Total	424	100	



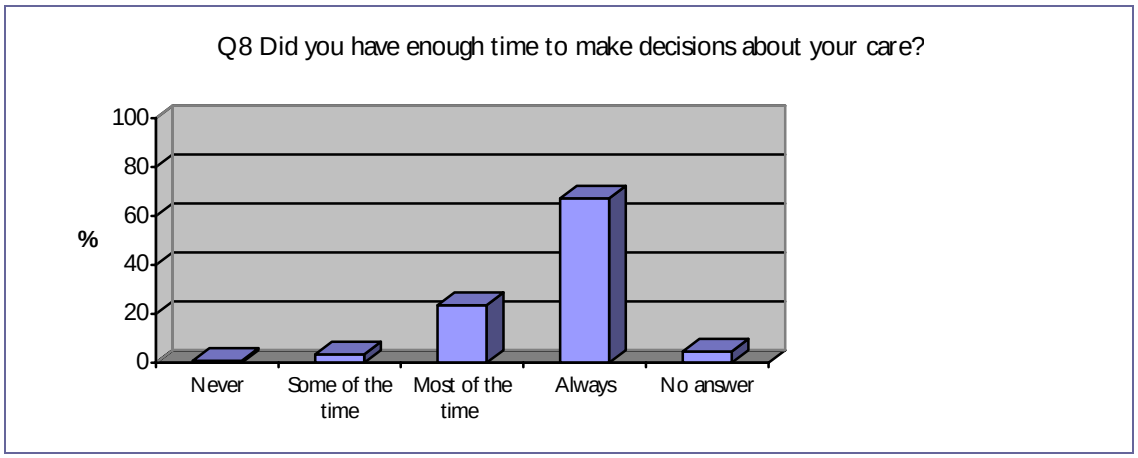
Q7 Did you have the opportunity to ask questions when you wanted to?

	N	Average (%)	Range (%)
Never	3	0.7	0.0 – 2.4
Some of the time	9	2.1	0.0 – 6.8
Most of the time	78	18.4	10.5 – 25.9
Always	319	75.2	66.7 – 87.7
No answer	15	3.5	1.7 – 7.1
Total	424	100	



Q8 Did you have enough time to make decisions about your care?

	N	Average (%)	Range (%)
Never	4	0.9	0.0 – 4.3
Some of the time	15	3.5	0.0 – 7.0
Most of the time	100	23.6	14.0 – 31.0
Always	285	67.2	55.3 – 80.7
No answer	20	4.7	1.7 – 9.5
Total	424	100	



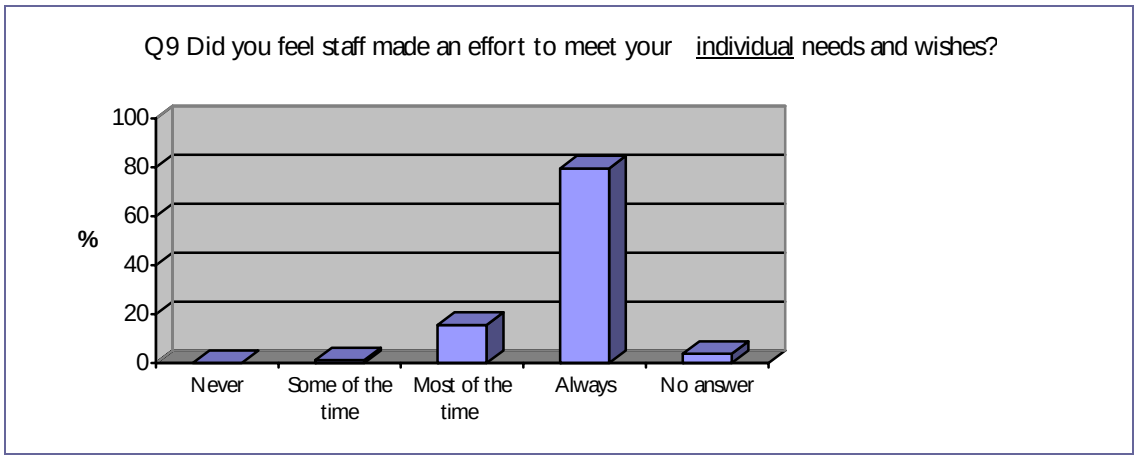
Views of inpatients on the support and courtesy of staff

A number of questions were asked in the survey about inpatient views on the support and courtesy of the staff looking after them on the ward. Generally respondents were very positive in the support they received from staff. 80% (a higher proportion than last year) felt that staff always made an effort to meet their individual needs and wishes and 16% felt they did most of the time. No one felt that staff never made an effort.

The vast majority of inpatients generally felt that staff were always respectful and that staff respected their privacy: 89% felt they were always treated with respect and a similar percentage (89%) felt that their privacy was always respected, eg when being examined or during discussions with staff. This is an increase on last survey for respect of privacy. None of the inpatients felt that they were not treated with respect in any way, apart from one patient who felt their privacy was never respected.

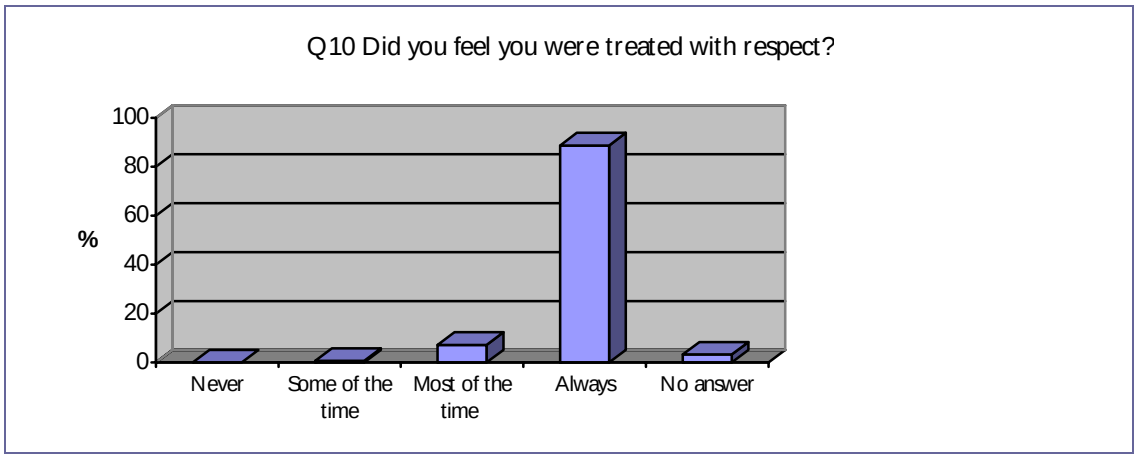
Q9 Did you feel staff made an effort to meet your individual needs and wishes?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	5	1.2	0.0 – 2.4
Most of the time	66	15.6	3.5 – 25.6
Always	337	79.5	72.1 – 89.5
No answer	16	3.8	0.0 – 7.0
Total	424	100	



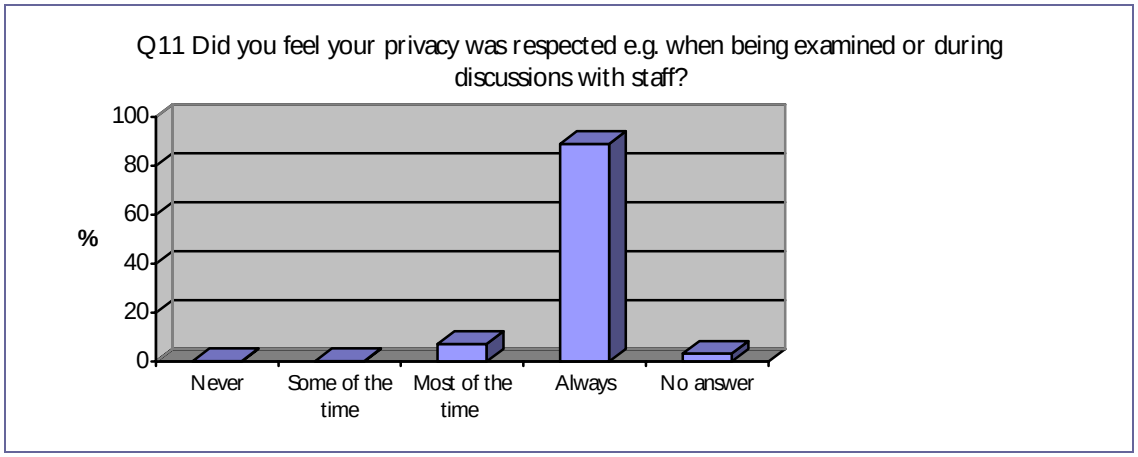
Q10 Did you feel you were treated with respect?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	3	0.7	0.0 – 2.2
Most of the time	31	7.3	1.8 – 13.8
Always	376	88.7	82.8 – 93.0
No answer	14	3.3	0.0 – 7.0
Total	424	100	



Q11 Did you feel your privacy was respected , eg when being examined or during discussions with staff?

	N	Average (%)	Range (%)
Never	1	0.2	0.0 – 2.1
Some of the time	1	0.2	0.0 – 2.2
Most of the time	31	7.3	0.0 – 15.5
Always	377	88.9	82.8 – 93.2
No answer	14	3.3	0.0 – 7.0
Total	424	100	



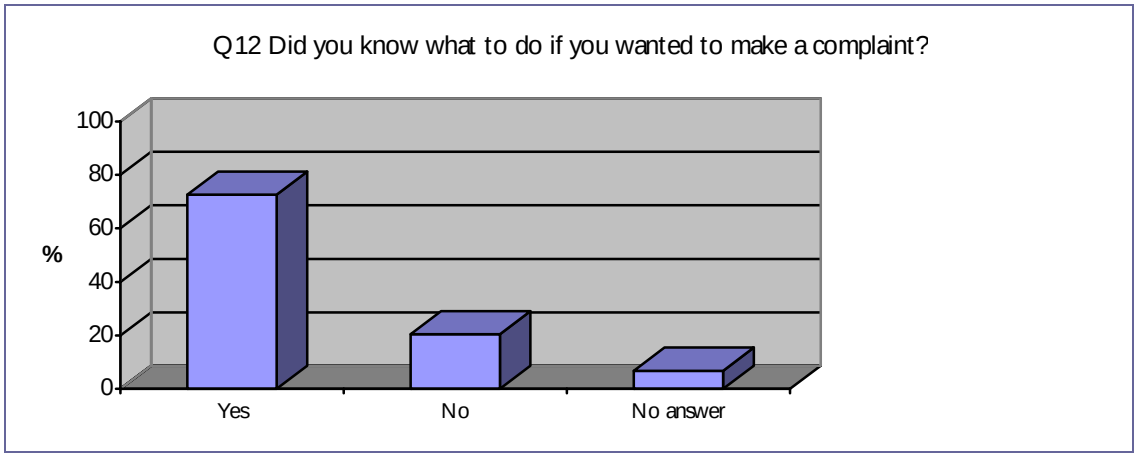
Inpatient facilities and services

The survey concentrated on general questions about facilities and services available to inpatients, which would apply to all hospices. It asked about awareness of how to make a complaint, what they thought about the quality of the catering, access to food other than at meal times and also views on the hospice and ward buildings themselves by asking questions about the general environment, surroundings and the cleanliness of the premises.

73% of respondents were aware of how to make a complaint compared to 21% who were not (an increase compared to the last survey). When asked to rate the following facilities and services they were viewed by the majority to be of a high standard and rated as excellent: the cleanliness of the premises (72%), the quality of the catering (67%), the access to food other than at meal times (53%) and the general environment and surroundings (79%). The lowest ratings were therefore related to meal times, with the quality of the catering and access to food outside normal meal times in particular. However ratings of excellent were quite variable, among the benchmark hospices individually for all of these aspects (particularly the quality of the catering) so there is also room for improvement for some hospices in all these areas. Respondents were invited to make further comments on these facilities and services which can be found in the 5.4 textual comments sections of this report.

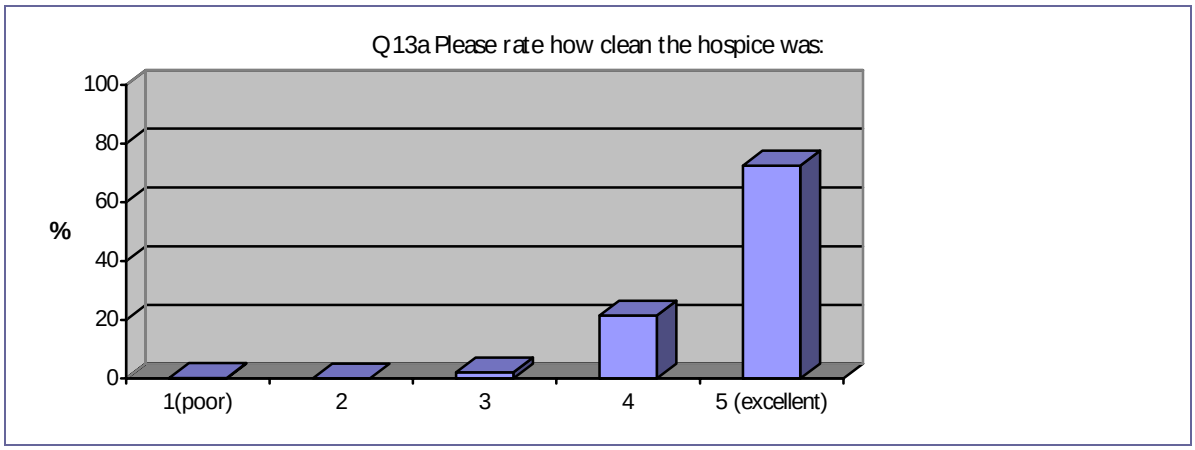
Q12 Did you know what to do if you wanted to make a complaint?

	N	Average (%)	Range (%)
Yes	308	72.6	57.4 – 81.4
No	87	20.5	11.4 – 31.9
No answer	29	6.8	3.5 – 10.9
Total	424	100	



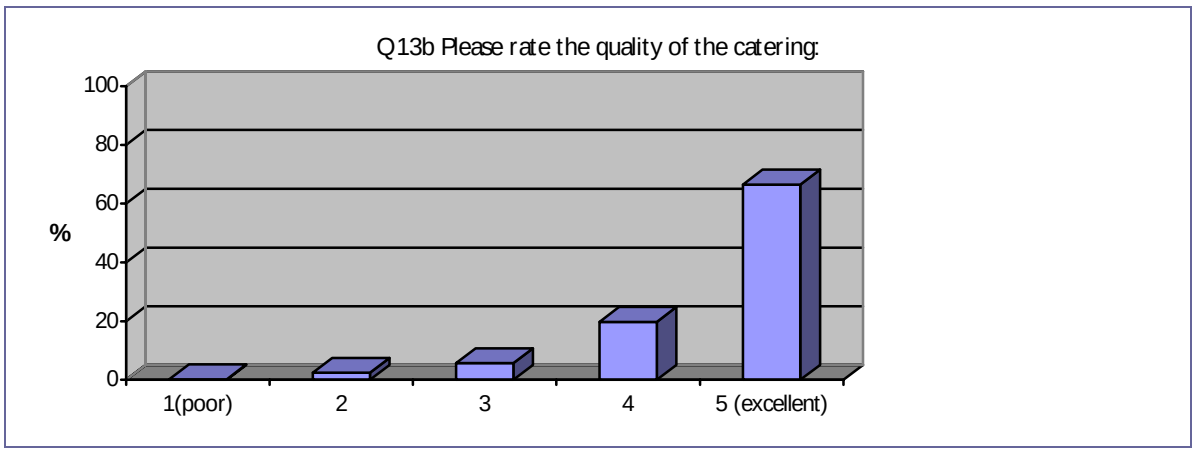
Q13a Please rate how clean the hospice was:

	N	Average (%)	Range (%)
1. Poor	1	0.2	0.0 – 2.3
2.	0	0.0	0.0 – 0.0
3.	9	2.1	0.0 – 6.9
4.	91	21.5	12.8 – 29.3
5. Excellent	307	72.4	62.1 – 83.0
No answer	16	3.8	0.0 – 9.3
Total	424	100	



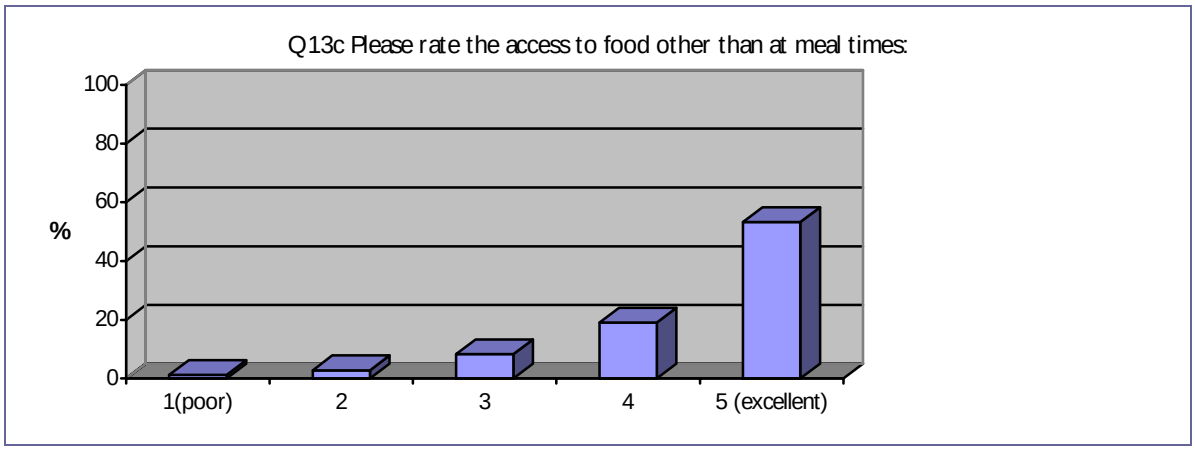
Q13b Please rate the quality of the catering:

	N	Average (%)	Range (%)
1. Poor	1	0.2	0.0 – 2.3
2.	10	2.4	0.0 – 6.9
3.	24	5.7	2.3 – 10.3
4.	84	19.8	9.3 – 34.5
5. Excellent	282	66.5	46.6 – 83.7
No answer	23	5.4	0.0 – 11.6
Total	424	100	



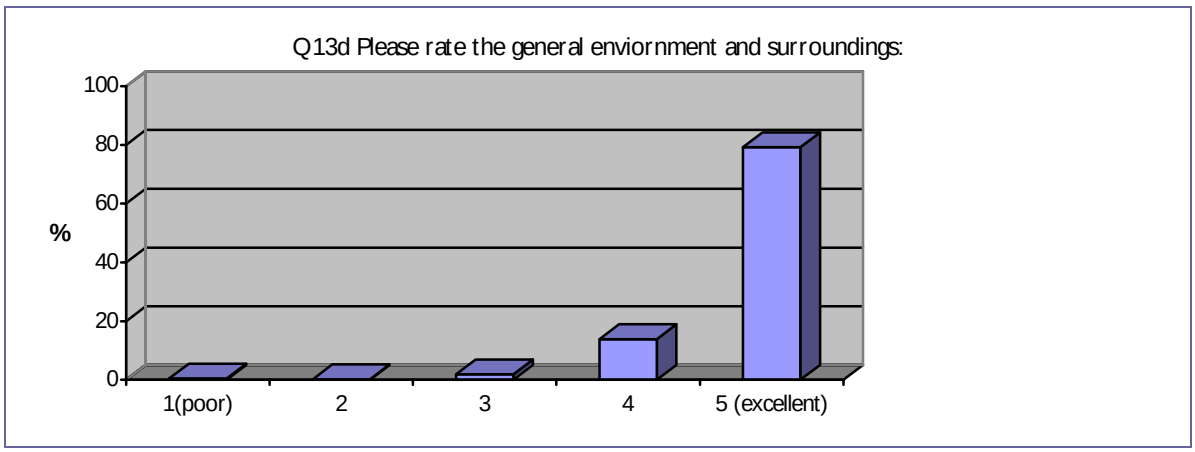
Q13c Please rate the access to food other than at meal times:

	N	Average (%)	Range (%)
1. Poor	5	1.2	0.0 – 4.5
2.	12	2.8	0.0 – 5.2
3.	35	8.3	2.3 – 17.2
4.	81	19.1	6.8 – 29.5
5. Excellent	226	53.3	40.9 – 68.1
No answer	65	15.3	6.4 – 25.6
Total	424	100	



Q13d Please rate the general environment and surroundings:

	N	Average (%)	Range (%)
1. Poor	2	0.5	0.0 – 2.3
2.	1	0.2	0.0 – 1.8
3.	8	1.9	0.0 – 8.7
4.	59	13.9	4.7 – 31.0
5. Excellent	336	79.2	65.5 – 90.7
No answer	18	4.2	1.7 – 11.6
Total	424	100	



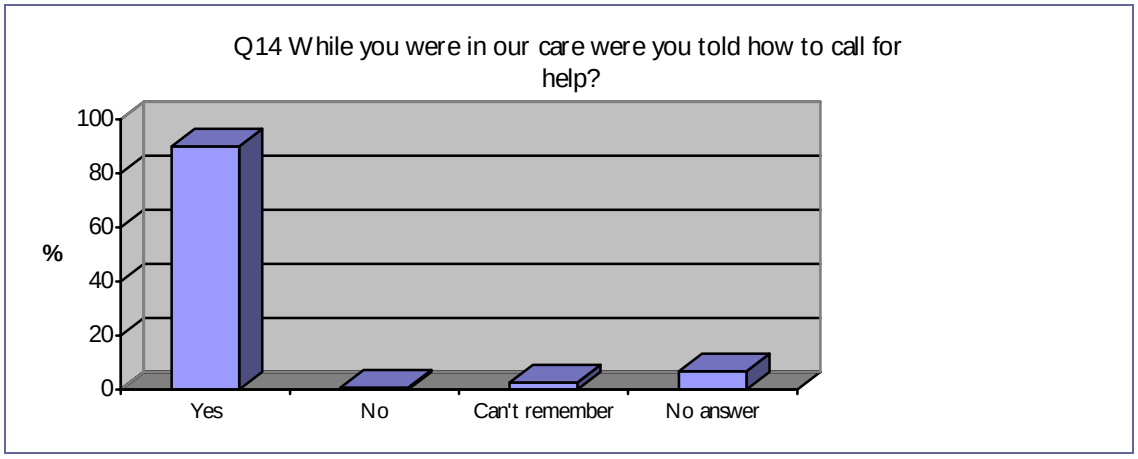
Inpatients calling for assistance

The majority of inpatients (90%) were told how to call for assistance while they were in hospice care. Only three respondents reported that they were not told. 32 respondents (8%) did not need to call for assistance, when they were an inpatient. Of those who did need to call for assistance the majority 70% were always satisfied with the response they got, (which is lower compared to the previous survey. 18% were satisfied most of the time with the response. The answer to this question was quite varied between the individual hospices, with patient s from some hospices being much happier with the response compared to others (44%-83%).

Q14 While you were in our care were you told how to call for help?

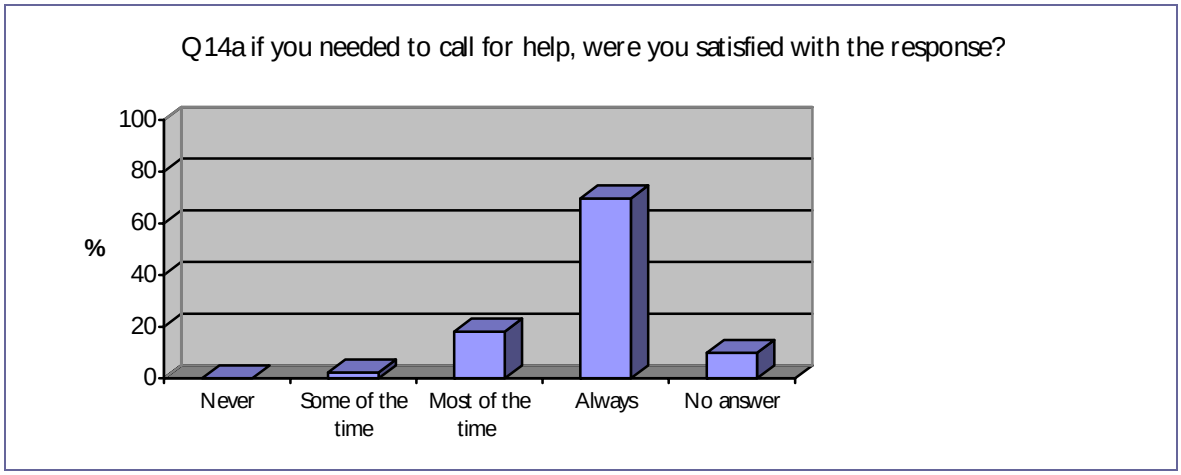
	N	Average (%)	Range (%)
Yes	381	89.9	74.5 – 97.7
No	3	0.7	0.0 – 4.7
Can't remember	11	2.6	0.0 – 8.5

No answer	29	6.8	2.3 – 14.9
Total	424	100	



Q14a If you needed to call for help, were you satisfied with the response?

	N	Average (%)	Range (%)
Never	0	0.0	0.0 – 0.0
Some of the time	9	2.3	0.0 – 7.7
Most of the time	71	18.1	7.5 – 30.8
Always	273	69.6	44.2 – 83.0
No answer	39	9.9	2.6 – 21.4
Total	392	100	
Not applicable as did not need to call for help: 32			

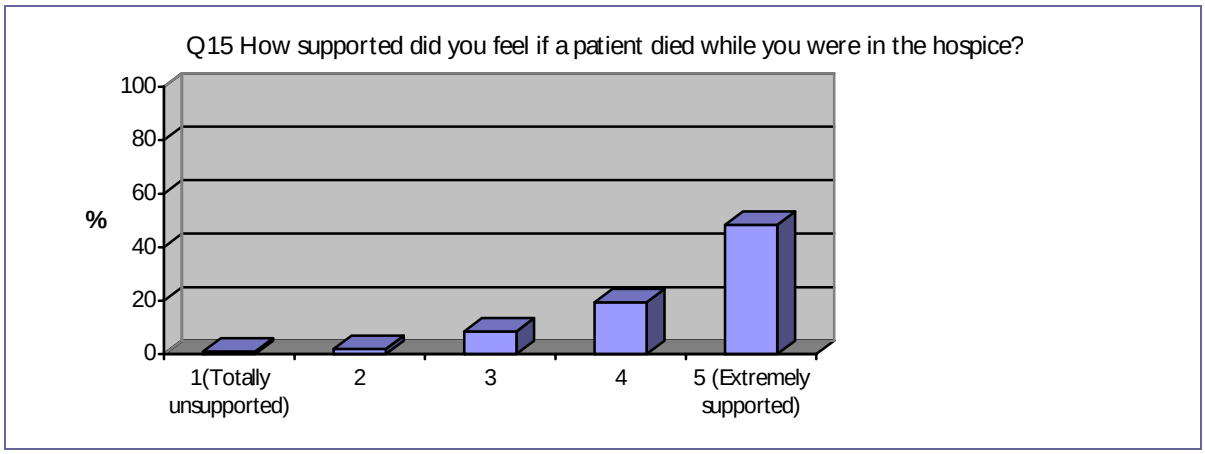


Support if someone had died

A new question was included in the inpatient questionnaire for this year's survey. This was about supported patients felt if a fellow patient died while they were in the hospice. Half of the inpatients were not aware that others had died whilst they had been in the hospice. For those who had been/ or were made aware 48% (just under half) felt they had been extremely supported and only two respondents (1%) felt they were totally unsupported. However, 21% of patients chose not to answer this question, which is the highest rate of non-completion compared to other questions in the survey. Again, there was variation in the number who felt supported and in the number who answered depending on the hospice they stayed in.

Q15 How supported did you feel if a patient died while you were in the hospice?

	N	Average (%)	Range (%)
1. Totally unsupported	2	0.9	0.0 – 7.1
2.	4	1.9	0.0 – 6.3
3.	18	8.5	0.0 – 17.9
4.	41	19.4	7.1 – 35.7
5. Extremely supported	102	48.3	25.0 – 64.0
No answer	44	20.9	4.0 – 32.1
Total	211	100	
Not applicable as was not aware of anyone dying: 213			



5.3 Average inpatient results overall (48 hospices)

The following results report the average responses of all participants aggregated together from all 48 hospices who took part in the inpatient questionnaire at discharge. The total number of completed questionnaires received from inpatients was 1052. 1057 questionnaires were actually received but five only included comments and so are excluded from these aggregated results.

Service: Inpatient N: 1052

Q1 During your time on the ward, were you aware of a leaflet or booklet?

Yes:	No	Can't remember	No answer
710 (67.5%)	258 (24.5%)	66 (6.3%)	18 (1.7%)

Q2a If you looked at the leaflet or booklet, was it easy to understand?

Yes	No	Can't remember	No answer
624 (90.8%)	7 (1.0%)	21 (3.1%)	35 (5.1%)
Did not look at the leaflet or booklet: 41			
Not applicable: 324			

Q2b If you looked at the leaflet or booklet, was it helpful?

Yes	No	Can't remember	No answer
605 (88.1%)	5 (0.7%)	29 (4.2%)	48 (7.0%)
Did not look at the leaflet or booklet: 41			
Not applicable: 324			

Q2c If you looked at the leaflet or booklet, was there anything that was not correct?

Yes	No	Can't remember	No answer
17 (2.5%)	489 (71.2%)	122 (17.8%)	59 (8.6%)
Did not look at the leaflet or booklet: 41			
Not applicable: 324			

Q3a While you were an inpatient did the staff involved in your care introduce themselves?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	35 (3.3%)	162 (15.4%)	823 (78.2%)	30 (2.9%)

Q3b While you were an inpatient did the staff involved in your care explain what they were doing?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	28 (2.7%)	175 (16.6)	823 (78.2%)	24 (2.3%)

Q4 Overall, did you have confidence in the staff who were caring for you?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	6 (0.6%)	139 (13.2%)	887 (84.3%)	19 (1.8%)

Q5 Overall, how satisfied were you with your involvement in planning your care?

Very dissatisfied	Not satisfied	Satisfied	Very satisfied	No answer
24 (2.3%)	10 (1.0%)	237 (22.5%)	746 (70.9%)	35 (3.3%)

Q6 Overall, did you understand the explanations given to you about your treatment and care?

Never	Some of the time	Most of the time	Always	No explanation	No answer

				given	
2 (0.2%)	33 (3.1%)_	244 (23.2%)	732 (69.6%)	6 (0.6%)	35 (3.3%)

Q7 Did you have the opportunity to ask questions when you wanted to?

Never	Some of the time	Most of the time	Always	No answer
4 (0.4%)	19 (1.8%)	159 (15.1%)	837 (79.6%)	33 (3.1%)

Q8 Did you have enough time to make decisions about your care?

Never	Some of the time	Most of the time	Always	No answer
6 (0.6%)	32 (3.0%)	226 (21.5%)	745 (70.8%)	43 (4.1%)

Q9 Did you feel staff made an effort to meet your individual needs and wishes?

Never	Some of the time	Most of the time	Always	No answer
0 (0.0%)	14 (1.3%)	161 (15.3%)	841 (79.9%)	36 (3.4%)

Q10 Did you feel you were treated with respect?

Never	Some of the time	Most of the time	Always	No answer
0 (0%)	5 (0.5%)	52 (4.9%)	960 (91.3%)	35 (3.3%)

Q11 Did you feel your privacy was respected , eg when being examined or during discussions with staff?

Never	Some of the time	Most of the time	Always	No answer
1 (0.1%)	4 (0.4%)	65 (6.2%)	947 (90.0%)	35 (3.3%)

Q12 Did you know what to do if you wanted to make a complaint?

Yes	No	No answer
764 (72.6%)	214 (20.3%)	74 (7.0%)

Q13 Please rate the following by circling your response:

	1 =Poor → 5 =Excellent					No answer
	1	2	3	4	5	
How clean the hospice was	1 (0.1%)	1 (0.1%)	20 (1.9%)	185 (17.6%)	804 (76.4%)	41 (3.9%)
The quality of the catering	4 (0.4%)	18 (1.7%)	58 (5.5%)	211 (20.1%)	703 (66.8%)	58 (5.5%)
Access to food other than at mealtimes:	10 (1.0%)	23 (2.2%)	85 (8.1%)	201 (19.1%)	584 (55.5%)	149 (14.2%)
The general environment and surroundings:	4 (0.4%)	2 (0.2%)	15 (1.4%)	132 (12.5%)	855 (81.3)	44 (4.2%)

Q14 While you were in our care were you told how to call for help?

Yes	No	Can't remember	No answer
942 (89.5%)	6 (0.6%)	26 (2.5%)	78 (7.4%)

Q14a If you needed to call for help, were you satisfied with the response?

Never	Some of the time	Most of the time	Always	No answer
2 (0.2%)	17 (1.7%)	154 (15.8%)	712 (73.1%)	89 (9.1%)
Did not need to call for help: 78				

Q15 How supported did you feel if a patient died while you were in the hospice?

1 =Totally unsupported → 5=Extremely supported					
1	2	3	4	5	No answer
12 (2.4%)	7 (1.4%)	39 (7.9%)	89 (18.1%)	217 (44.2%)	127 (25.9%)
Not applicable as was not aware of anyone dying: 561					

5.4. Inpatient textual comments (48 hospices)

Each participating hospice has been given inpatients' comments about their individual hospice. This section summarises inpatients' comments across all the hospices involved in the inpatient survey.

The questionnaire had space for patients to write in and elaborate on their answers to 'tick box' questions and to make some general comments at the end of the questionnaire. Numerous comments were received about information, the care staff, explanations about care, catering, facilities, the general environment of the hospice.

The majority of comments were highly favourable and overall there were only 313 (26%) out of a total of 1171 comments that identified issues for hospices to address. The summary of the comments that follows focuses mainly on the latter and it should be noted that many of these are made by one or two people only.

Information leaflets (Q2)

While comments were not very numerous in this section, a higher proportion of them might be of use to hospices. Many patients thought the booklet was 'clear' and 'informative, however inpatients also had problems taking information in due to their health, being too tired because of their illness, or they were partially sighted. In some cases family members read the leaflet for them, but one patient suggested that the font size should be larger; another suggested that information on audio cassette would have been more useful, others preferred talking to staff about any information they needed.

Some patients felt there was other information that would be useful to include (local public transport, directions/map, meal times, additional contacts and services), or the leaflet mentioned things that were inaccurate, where items were out of date, or incorrect information was given about charges, the local bus number and the availability of towels.

Some patients commented that they thought the leaflet should be given out more to patients, but it was also suggested that it should be given to visitors and the general public so they are more aware of what hospices do. One patient assumed the booklet was for staff and not for patients or the public.

Care staff (Q4)

The comments about confidence in staff were overwhelmingly positive, describing staff as 'excellent', 'caring' and highly 'dedicated' people who had time for their patients. Some patient compared the care of the staff in the hospice to be better than other hospitals and places they had stayed as inpatients. Some patients said:

> *'Care I got from staff was good and no trouble. They always had a cheery smile and asked how you were feeling''*
>
> *'I have never met such caring and compassionate staff, every one of them are wonderful'*
>
> *'The staff were fantastic, helpful, caring, could not do enough for you. Made you feel so special you didn't want to go home'.*

Compared to daycare patients there were a few more negative comments about staff, mainly centred around an incident relating to lack of communication between staff (at time of hand-over for example), time taken to answer the call button or bell, or a member of staff being less helpful or caring than others. Other comments were about not being able to see name badges, staff not having appropriate skills, eg trainee not using equipment properly. Some said the night staff were not as thoughtful or caring, or they were loud at night. However this varied as other patients said the night staff were just as good or better. Some patients felt they were unable to judge the care of the staff at the time as they were too unwell.

Care planning (Q5)

Although only a few comments were made, they did point to problems in communication. Inpatients wanted to have more direct communication with staff, for them to have more time to explain issues and for patients to be told why something was happening , eg why their medication was changed, or why they were going to see the physiotherapist. One patient said they would have liked their family to have been more involved in the planning of their care. A few patients simply wrote that they were not involved in the planning of their care, but generally they were not worried about this. One patient commented that it wouldn't have been useful as they were 'not with it' most of the time because of the medication they were on. Another felt that although they were consulted it was difficult to understand and make decisions when they feeling so ill.

Explanations about care (Q6)

Although some patients said were happy with explanations given and they were clear, other patients did suggest ways to make explanations clearer. Some wanted more information in writing, especially at times when they were feeling confused, unwell and unable to retain all the information. Other suggestions included the use of more simple language, for explanations to be repeated, for staff to speak slower and take more time over explanations, particularly if patients were drowsy or hard of hearing.

Cleanliness of premises, catering, access to food other than at set meal times, general environment/surroundings (Q13)

This section of the questionnaire prompted many positive comments, including:

> *'Quality of staff and management of establishment out of this world'*
>
> *'If I was paying £600 a night to stay at the Ritz Hotel, I couldn't get any better service'*
>
> *'A wonderful place to be able to come to and be looked after and treated as a whole person and all my needs met. What would we do without you'*

The facilities and service at the hospice exceeded the expectation of some patients, however some patients remarked on some aspects which were not rated so highly. A poor standard of cleanliness was remarked upon by one or two patients, more so in relation to the toilets.

Catering generated comments about specific foods they would like or the way food was served or cooked, others wanted more choice on the menu. A few respondents commented that the food was not hot enough. One patient said they liked the china and crockery used but found them heavy to manage. Another suggested that the menu be described in plainer English that they could understand. Due to the question in the questionnaire about access to food other than at meal times, some patients commented that they didn't understand that they were able to have food outside of meal times, or they weren't aware if they were able to do this in their hospice.

Other comments about facilities included, problems with hot water, wanting a TV room, more entertainment and time in lounge areas. Other patients also commented that it was sometimes noisy when visitors were in the hospice, one wanted more fresh air while another said it was too cold in the lounge area, extensive building work was also noted. On patient commented that they liked the 'little extra touches' of newspapers, soft drinks and arranging flowers.

Overall comments (Q15)

At the end of the questionnaire many inpatients took the opportunity to make remarks about their hospice stay overall and the majority of these were favourable:

'The place is one in a million'

'It is a wonderful hospice. My little piece of heaven'

'I don't think it would be possible to improve on perfection'

'Marks out of 10 - a mere 12!!!!'

Among the more critical comments, the same overall problems were raised that had appeared in earlier sections of the questionnaire, such as, food, noise, staff numbers, access to lounge/TV areas. However, patients also took the opportunity to raise new issues at the end of the question. The most frequent issues are commented on here. This included better bathing facilities , eg more showers, hand rails, disabled access and a Jacuzzi bath. Some additional issues were raised about the funding for hospices and more donations from patients and more activities to relieve boredom and loneliness.

More sensitive issues were also raised, these included respite patients feeling that their allocated ward was inappropriate, it was suggested that it would be better if patients for respite care were in the same ward. Patients also commented that they were aware when a patient in their ward had died. It was felt that there was not enough privacy when this happens on the ward as conversations could be heard with the family which could be upsetting. For this reason and for the reasons of personal comfort, a number of patients suggested they would prefer a single room instead of being on a ward.

The questionnaire (Q16)

84 comments were made about the questionnaire and all but a quarter were complimentary. The small number of problems (usually made by one individual) included some questions not feeling relevant, eg respite patients, better layout by making sure questions and answers are on the same page, questionnaire could be longer, could be shorter, some questions overlapped and suggestion of a 'middle' answer in some of the questions so people do not have to sway one way or the other. A couple of patients also wondered why there was no space to provide their name and address details , another picked up that the return address was different on the questionnaire to that on the pre-paid envelope they had and one patient suggested that people should be informed in the letter that the questionnaire is double-sided.

6. Discussion

The report given to each participating hospice enables them to look at their own individual hospice results and compare themselves against the benchmark hospice results. Individual hospices can then benefit from seeing how well they 'fit' with other hospices who received a high response from the survey.

Aggregated results for the benchmark hospices and all participating hospices overall were very positive whether in a daycare or inpatient ward setting. They were both considered excellent and of a high standard in a number of broad areas, including the information provided, the care provided by staff, patient involvement and facilities available. Praise for hospice staff was particularly high in relation to the respect staff showed towards patients and the patients had confidence in the staff who were caring for them. Three quarters of respondents reported that staff always explained what they were doing and reported that they were always given an opportunity to ask questions.

There were some differences to note. Comparing the results of the two services indicates a higher level of satisfaction for daycare patients compared to inpatients overall. For example daycare patients had higher levels of satisfaction regarding information leaflets, introduction of staff, staff explanations about their care, confidence in staff care, involvement in care planning, understanding of explanations, staff meeting individual needs and wishes, respect from staff generally, the environment, surroundings and cleanliness of the hospice. The slightly lower level of satisfaction by inpatients may be due to the different nature of care and treatment they receive, being more complex and staying in the hospice for a longer period of time rather than the short visits provided by daycare services. However it is important to recognise that despite these differences the level of satisfaction with all of these areas was extremely high for both inpatient and daycare patients.

There were some weaker service areas in comparison to others, but most of these were still highly rated by the majority of patients overall. For example, the weaker service areas were the level of satisfaction with the quality of the catering, knowledge of how to make a complaint, the range of activities available in daycare, response time when calling for assistance and availability of food outside meal times for inpatients and patient involvement in the planning of their care.

Aspects of hospice care that were least satisfactory were related to support when a patient had died or had been discharged (daycare only). If they were aware that a patient had died, fewer than half of respondents felt they were well supported when this happened. The level of support felt by daycare was slightly lower when a patient had been discharged.

Judging from the written comments a similar pattern emerges with hospice patients being extremely satisfied with their care and full of praise for the staff. Some of the comments raised issues that hospices may wish to address, for example comments and suggestions frequently covered practical problems, such as transport, food, activities and facilities, but they also included issues about staffing levels and performance. The proportion of negative comments, or comments suitable for action, was slightly greater for inpatients than for daycare patients.

The results for benchmark hospices were very similar to the average results for all participating hospices. However it is interesting to note that slightly higher rates of excellence are to be found in many of the daycare benchmark results compared to the overall results including all participating hospices. Conversely slightly lower rates of excellence are reported for the inpatient benchmark, compared to the overall results.

Some comparison was made between the results for the 2006/07 survey and the previous survey. A difficulty with such comparison is that the hospices achieving the benchmark vary year on year and this needs to be taken into account when interpreting such results. The majority of results for daycare were just as positive as the last survey. Compared to the 2004/05 survey patients were less anxious before and after the first visit to daycare, felt safer on hospice transport, more satisfied with their involvement in the planning of their care, more staff were introducing themselves and explaining what they were doing to patients. Daycare patients were less satisfied with the support they received when patients had died or had been discharged and the quality of the catering.

The results for inpatients were more varied across the two surveys. A higher percentage felt that they were always given enough time to make decisions about their care, staff made an effort to meet their individual needs and wishes, that their privacy was respected and more knew the process for making a complaint, compared to the 2004/05 survey. However in the latest survey a lower proportion of inpatients reported that they found the information leaflet helpful and easy to understand, were happy with the response time to a call for assistance, were given the opportunity to ask questions and they had a lower satisfaction with their involvement in the planning of their care.

7. Considerations for the future

- This survey has been repeated for a second time to seek views of patients on the quality of the treatment and care provided as required by the Healthcare Commission. Given the similar nature of this year's results to the previous survey there is confidence in the results, indicating that it is worthwhile to continue.

- It is recommended that the survey should be repeated so that individual hospices participating in the survey can measure change in their quality of treatment and care over time. A more rigorous approach should be taken to measure the response rates systematically in participating hospices in future surveys in order to have a more accurate judgement of patients' willingness to complete the survey.

- The survey results are beneficial to the hospices taking part as it has allowed them to legitimately identify areas for improvement in their hospice and take appropriate action. This action may involve further investigation of the issue by consultation with patients. The consultation may be in the form of more qualitative methods of research, such as focus groups or meetings with patients and staff to discuss the issue.

- Key areas identified within some hospices were catering services, support when a patient had been discharged or died, daycare transport services, activities, user involvement in planning of care and treatment, information giving and understanding. Participating hospices should be encouraged to develop their own action plans where there is scope for improvement, identified from their individual results.

Results of the 2006/2007 Hospice Patient Survey

General Report

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